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U.S. Congress. House. Committee on Interstate and Foreign Commerce.
Subcommittee on Public Health and Welfare.
Mental Retardation Facilities.

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MENTAL RETARDATION FACILITIES

HEARINGS

BEFORE THE

SUBCOMMITTEE ON PUBLIC HEALTH AND WELFARE

OF THE

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

HOUSE OF REPRESENTATIVES

NINETIETH CONGRESS

FIRST SESSION

ON

H.R. 6430 and H.R. 7688

BILLS TO AMEND THE PUBLIC HEALTH LAWS RELATING TO MENTAL RETARDATION TO EXTEND, EXPAND, AND IMPROVE THEM, AND FOR OTHER PURPOSES

H.R. 5110

A BILL TO AMEND THE MENTAL RETARDATION FACILITIES AND COMMUNITY MENTAL HEALTH CENTERS CONSTRUCTION ACT OF 1963 TO PROVIDE GRANTS FOR COSTS OF INITIATING SERVICES IN COMMUNITY MENTAL RETARDATION FACILITIES

APRIL 25 AND 26, 1967

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MENTAL RETARDATION FACILITIES

TUESDAY, APRIL 25, 1967

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON PUBLIC HEALTH AND WELFARE
OF THE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met at 10 a.m., pursuant to notice, in room 2123, Rayburn House Office Building, Hon. John Jarman (chairman of the subcommittee) presiding.

Mr. JARMAN. The subcommittee will please be in order. The hearing today is on H.R. 6430, introduced by Chairman Staggers of the full committee at the request of the administration; H.R. 7688, introduced by our colleague, Mr. Carey, which is identical to the chairman's bill except with respect to one section; and H.R. 5110, introduced by our colleague, Mr. Waldie.

H.R. 6430 proposes to extend through fiscal 1972 the existing program under which matching grants are made for the construction of university-affiliated clinical facilities for the mentally retarded and community mental retardation facilities.

The bill adds a new part D to existing law which would provide matching grants following the same formula as set out in the Community Mental Health Centers Act for the costs of compensation of professional and technical personnel for the initial operation of new facilities for the mentally retarded or of new services in existing facilities for the mentally retarded.

The bill also provides an amendment similar to the amendment agreed to by the full committee in the mental health legislation, providing for enforcement of standards of operation of facilities or centers.

H.R. 7688 contains an additional section extending to June 30, 1972, the program of research and demonstration projects for the mentally retarded and of education of teachers of handicapped children.

H.R. 5110 would extend the current authorization for construction assistance, and would provide matching grants on a declining basis, the same as the other two bills, for the costs of professional and technical personnel.

(The bills referred to, and departmental reports thereon, follow:)

[H.R. 6430, 90th Cong., 1st sess.]

A BILL To amend the public health laws relating to mental retardation to extend, expand, and improve them, and for other purposes

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Mental Retardation Amendments of 1967".

GRANTS FOR CONSTRUCTION OF UNIVERSITY-AFFILIATED MENTAL RETARDATION CLINICAL FACILITIES

SEC. 2. (a) The first sentence of section 121 of the Mental Retardation Facilities Construction Act (42 U.S.C. 2661) is amended by striking out "and $10,000,000 each for the fiscal year ending June 30, 1966, and the fiscal year ending June 30, 1967" and inserting in lieu thereof "$10,000,000 each for the fiscal year ending June 30, 1966, the fiscal year ending June 30, 1967, and the fiscal year ending June 30, 1968, and such sums as may be necessary for the next four fiscal years".

(b) Such sentence is further amended by inserting "(which, for purposes of this part, includes other neurological handicapping conditions found by the Secretary to be sufficiently related to mental retardation to warrant inclusion in this part)" after "the mentally retarded" the first time it appears therein, and by inserting "including research incidental or related to any of the foregoing activities," before "there are authorized to be appropriated".

(c) Section 125 of such Act (42 U.S.C. 2665) is amended by striking out "four", and by striking out "June 30, 1967" and inserting in lieu thereof "June 30, 1972".

GRANTS FOR CONSTRUCTION OF COMMUNITY FACILITIES FOR THE MENTALLY RETARDED

SEC. 3. (a) Section 131 of the Mental Retardation Facilities Construction Act (42 U.S.C. 2671) is amended by striking out "and $30,000,000 for the fiscal year ending June 30, 1968" and inserting in lieu thereof "$30,000,000 for the fiscal year ending June 30, 1968, and such sums as may be necessary for the next four fiscal years".

(b) Section 137 of such Act is amended by striking out "four", and by striking out "1968" and inserting in lieu thereof "1972".

GRANTS FOR STAFFING OF COMMUNITY MENTAL RETARDATION FACILITIES

SEC. 4. The Mental Retardation Facilities Construction Act is further amended (1) by amending the heading thereof to read "TITLE I—FACILITIES FOR THE MENTALLY RETARDED", and (2) by adding at the end thereof the following new part:

"PART D—GRANTS FOR THE COST OF PROFESSIONAL AND TECHNICAL PERSONNEL OF COMMUNITY MENTAL RETARDATION FACILITIES

"AUTHORIZATION OF GRANTS

"SEC. 141. (a) For the purpose of assisting in the establishment and initial operation of facilities for the mentally retarded providing all or part of a program of comprehensive services for the mentally retarded principally designed to serve the needs of the particular community or communities in or near which the facility is situated, the Secretary may, in accordance with the provisions of this part, make grants to meet, for the temporary periods specified in this section, a portion of the costs (determined pursuant to regulations under section 144) of compensation of professional and technical personnel for the initial operation of new facilities for the mentally retarded or of new services in facilities for the mentally retarded.

"(b) Grants for such costs for any facility for the mentally retarded under this part may be made only for the period beginning with the first day of the first month for which such a grant is made and ending with the close of four years and three months after such first day; and such grants with respect to any such facility may not exceed 75 per centum of such costs for the period ending with the close of the fifteenth month following such first day, 60 per centum of such costs for the first year thereafter, 45 per centum of such costs for the second year thereafter, and 30 per centum of such costs for the third year thereafter.

"(c) In making such grants, the Secretary shall take into account the relative needs of the several States for services for the mentally retarded, their relative financial needs, and their populations.

"APPLICATIONS AND CONDITIONS FOR APPROVAL

"SEC. 142. (a) Grants under this part with respect to any facility for the mentally retarded may be made only upon application, and only if—

"(1) the applicant is a public or nonprofit private agency or organization which owns or operates the facility;

"(2)(A) a grant was made under part C of this title to assist in financing the construction of the facility or (B) the type of service to be provided as part of such program with the aid of a grant under this part was not previously being provided by the facility with respect to which such application is made;

"(3) the Secretary determines that there is satisfactory assurance that Federal funds made available under this part for any period will be so used as to supplement and, to the extent practical, increase the level of State, local, and other non-Federal funds for mental retardation services that would in the absence of such Federal funds be made available for (or under) the program described in paragraph (2) of this subsection, and will in no event supplant such State, local, and other non-Federal funds; and

"(4) in the case of an applicant in a State which has in existence a State plan relating to the provision of services for the mentally retarded, the services to be provided by the facility are consistent with the plan.

"(b) No grant may be made under this part after June 30, 1972, with respect to any facility for the mentally retarded or with respect to any type of service provided by such a facility unless a grant with respect thereto was made under this part prior to July 1, 1972.

"PAYMENTS

"SEC. 143. Payment of grants under this part may be made (after necessary adjustment on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and on such terms and conditions and in such installments, as the Secretary may determine.

"REGULATIONS

"SEC. 144. The Secretary shall prescribe general regulations concerning the eligibility of facilities under this part, determination of eligible costs with respect to which grants may be made, and the terms and conditions (including those specified in section 142) for approving applications under this part.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 145. There are authorized to be appropriated $7,000,000 for the fiscal year ending June 30, 1968, and such sums as may be necessary for the next four fiscal years, to enable the Secretary to make initial grants to facilities for the mentally retarded under the provisions of this part. For the fiscal year ending June 30, 1969, and each of the next seven years, there are authorized to be appropriated such sums as may be necessary to make grants to such facilities which have previously received a grant under this part and are eligible for such a grant for the year for which sums are being appropriated under this sentence."

SEC. 5. Paragraph (7) of section 134 of the Mental Retardation Facilities Construction Act (42 U.S.C. 2674), is amended by inserting before the semicolon at the end thereof "and, effective July 1, 1969, provide for enforcement of such standards with respect to projects approved by the Secretary under this part after June 30, 1967".

[H.R. 7688, 90th Cong., 1st sess.]

A BILL To amend the public health laws relating to mental retardation to extend, expand, and improve them, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Mental Retardation Amendments of 1967".

GRANTS FOR CONSTRUCTION OF UNIVERSITY-AFFILIATED MENTAL RETARDATION CLINICAL FACILITIES

SEC. 2. (a) The first sentence of section 121 of the Mental Retardation Facilities Construction Act (42 U.S.C. 2661) is amended by striking out "and $10,000,000 each for the fiscal year ending June 30, 1966, and the fiscal year ending June 30, 1967" and inserting in lieu thereof "$10,000,000 each for the fiscal year ending June 30, 1966, the fiscal year ending June 30, 1967, and the fiscal year ending June 30, 1968, and such sums as may be necessary for the next four fiscal years".

(b) Such sentence is further amended by inserting "(which, for purposes of this part, includes other neurological handicapping conditions found by the Secretary

to be sufficiently related to mental retardation to warrant inclusion in this part)" after "the mentally retarded" the first time it appears therein, and by inserting "including research incidental or related to any of the foregoing activities," before "there are authorized to be appropriated".

(c) Section 125 of such Act (42 U.S.C. 2665) is amended by striking out "four", and by striking out "June 30, 1967" and inserting in lieu thereof "June 30, 1972".

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(b) Section 137 of such Act is amended by striking out "four", and by striking out "1968" and inserting in lieu thereof "1972".

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"PART D—GRANTS FOR THE COST OF PROFESSIONAL AND TECHNICAL PERSONNEL OF COMMUNITY MENTAL RETARDATION FACILITIES

"AUTHORIZATION OF GRANTS

"SEC. 141. (a) For the purpose of assisting in the establishment and initial operation of facilities for the mentally retarded providing all or part of a program of comprehensive services for the mentally retarded principally designed to serve the needs of the particular community or communities in or near which the facility is situated, the Secretary may, in accordance with the provisions of this part, make grants to meet, for the temporary periods specified in this section, a portion of the costs (determined pursuant to regulations under section 144) of compensation of professional and techincal personnel for the initial operation of new facilities for the mentally retarded or of new services in facilities for the mentally retarded.

"(b) Grants for such costs for any facility for the mentally retarded under this part may be made only for the period beginning with the first day of the first month for which such a grant is made and ending with the close of four years and three months after such first day; and such grants with respect to any such facility may not exceed 75 per centum of such costs for the period ending with the close of the fifteenth month following such first day, 60 per centum of such costs for the first year thereafter, 45 per centum of such costs for the second year thereafter, and 30 per centum of such costs for the third year thereafter.

"(c) In making such grants, the Secretary shall take into account the relative needs of the several States for services for the mentally retarded, their relative financial needs, and their populations.

"APPLICATIONS AND CONDITIONS FOR APPROVAL

"SEC. 142. (a) Grants under this part with respect to any facility for the mentally retarded may be made only upon application, and only if—

"(1) the applicant is a public or nonprofit private agency or organization which owns or operates the facility;

"(2)(A) a grant was made under part C of this title to assist in financing the construction of the facility or (B) the type of service to be provided as part of such program with the aid of a grant under this part was not previously being provided by the facility with respect to which such application is made;

"(3) the Secretary determines that there is satisfactory assurance that Federal funds made available under this part for any period will be so used as to supplement and, to the extent practical, increase the level of State, local, and other non-Federal funds for mental retardation services that would in the absence of such Federal funds be made available for (or under)

the program described in paragraph (2) of this subsection, and will in no event supplant such State, local and other non-Federal funds; and

"(4) in the case of an applicant in a State which has in existance a State plan relating to the provision of services for the mentally retarded, the services to be provided by the facility are consistent with the plan.

"(b) No grant may be made under this part after June 30, 1972, with respect to any facility for the mentally retarded or with respect to any type of service provided by such a facility unless a grant with respect thereto was made under this part prior to July 1, 1972.

"PAYMENTS

"SEC. 143. Payment of grants under this part may be made (after necessary adjustment on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and on such terms and conditions and in such installments, as the Secretary may determine.

"REGULATIONS

"SEC. 144. The Secretary shall prescribe general regulations concerning the eligibility of facilities under this part, determination of eligible costs with respect to which grants may be made, and the terms and conditions (including those specified in sec. 142) for approving applications under this part.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 145. There are authorized to be appropriated $7,000,000 for the fiscal year ending June 30, 1968, and such sums as may be necessary for the next four fiscal years, to enable the Secretary to make initial grants to facilities for the mentally retarded under the provisions of this part. For the fiscal year ending June 30, 1969, and each of the next seven years, there are authorized to be appropriated such sums as may be necessary to make grants to such facilities which have previously received a grant under this part and are eligible for such a grant for the year for which sums are being appropriated under this sentence."

ENFORCEMENT OF STATE STANDARDS OF OPERATION

SEC. 5. Paragraph (7) of section 134 of the Mental Retardation Facilities Construction Act (42 U.S.C. 2674), is amended by inserting before the semicolon at the end thereof "and, effective July 1, 1969, provide for endorcement of such standards with respect to projects approved by the Secretary under this part after June 30, 1967".

EDUCATION OF HANDICAPPED CHILDREN

SEC. 6. (a) Section 302(a) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 (20 U.S.C. 618(a)) is amended by striking out "and" before "$14,000,000", and by inserting ", and such sums as may be necessary for the next three fiscal years," after "June 30, 1969".

(b) Section 7 of the Act of September 6, 1958 (20 U.S.C. 617), is amended by striking out "and" before "$37,500,000", and by inserting ", and such sums as may be necessary for the next three fiscal years," after June 30, 1969".

[H.R. 5110, 90th Cong., 1st sess.]

A BILL To amend the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 to provide grants for costs of initiating services in community mental retardation facilities

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended by adding at the end of title I, the following new part:

"PART D—GRANTS FOR COSTS OF INITIATING SERVICES IN COMMUNITY MENTAL RETARDATION FACILITIES

"AUTHORIZATION OF GRANTS

"SEC. 141. (a) For the purpose of assisting public and nonprofit private agencies, organizations, or institutions to initiate, extend, and improve services in

facilities for the mentally retarded principally designed to serve the needs of the particular community or communities in or near which the facility is situated, the Secretary may, in accordance with the provisions of this part, make grants to meet not to exceed 75 per centum of the costs (determined pursuant to regulations under section 144) of providing services in such facilities for the mentally retarded.

"(b) In making such grants after June 30, 1968, the Secretary shall give preference to new or expanded services part of the cost of which will be borne out of State or local public funds.

"APPLICATIONS AND CONDITIONS FOR APPROVAL

"SEC. 142. Grants under this part with respect to any facility for the mentally retarded may be made only upon application, and only if—

"(1) the applicant is a public or nonprofit private agency, organization, or institution which owns or operates the facility;

"(2) the services to be provided by the facility will provide principally for persons residing in a particular community or communities in or near which such facility is situated, one or more of the types of services for the mentally retarded which are determined by the Secretary to be basic and necessary services for the mentally retarded;

"(3) the Secretary determines that the types of services to be supported are not sufficiently available in other facilities in said communities;

"(4) the Secretary determines that, with respect to the particular type or types of service to be so assisted, Federal financial assistance is not, in fact, available to the applicant under any other Act (or portion thereof) which is administered by the Department of Health, Education, and Welfare;

"(5) the Secretary determines that there is satisfactory assurance that Federal funds made available under this part for any period will be so used as to supplement and, to the extent practicable, increase the level of State, local, and other non-Federal funds for mental retardation services that would in the absence of such Federal funds be made available for the services described in paragraph (2) of this subsection, and will in no event supplant such State, local, and other non-Federal funds; and

"(6) in the case of an applicant in a State which has in existence a State plan relating to the provision of services for the mentally retarded, the services to be provided by the facility are consistent with the plan.

"PAYMENTS

"SEC. 143. Payment of grants under this part may be made (after necessary adjustment on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and on such terms and conditions and in such installments, as the Secretary may determine.

"REGULATIONS

"SEC. 144. (a) The Secretary shall prescribe general regulations concerning the eligibility of facilities under this part, determination of eligible costs with respect to which grants may be made, and the terms and conditions (including those specified in section 142) for approving applications under this part.

"(b) Payments under this part with respect to any project may be made for a period of not to exceed five years beginning with the commencement of the first fiscal year for which any payment is made.

"AUTHORIZATION OF APPROPRIATIONS

"SEC. 145. There are authorized to be appropriated $7,000,000 for the fiscal year ending June 30, 1968, $12,000 000 for the fiscal year ending June 30, 1969, $15,000,000 for the fiscal year ending June 30, 1970, $15,000,000, for the fiscal year ending June 30, 1971, and for the next four fiscal years, such, sums as may be necessary to enable the Secretary to make grants under the provisions of this part."

SEC. 2. Subsections (e) and (f) of section 401 of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, as amended, are amended to read as follows:

"(e) The term 'construction' includes construction of new buildings, acquisition of existing buildings, and expansion, remodeling, alteration, and renovation of existing buildings, and initial equipment of such new, newly acquired, expanded, remodeled, altered or renovated buildings.

"(f) The term 'cost of construction' includes the cost of architects' fees and acquisition of land in connection with construction, but does not include the cost of off-site improvements."

SEC. 3. This Act may be cited as the "Mental Retardation Facilities and Community Mental Health Centers Construction Act Amendments of 1967".

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
Washington, D.C., March 27, 1967.

Hon. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce,
House of Representatives, Washington, D.C.

DEAR MR. CHAIRMAN: This letter is in response to your request of March 13, 1967 for a report on H.R. 6430, the "Mental Retardation Amendments of 1967."

This bill embodies the provisions of a draft bill transmitted by us to the Congress in order to carry out the recommendations relating to the extension, expansion and improvement of mental retardation programs contained in the President's message to the Congress on the welfare of children.

We urge that your Committee give favorable consideration to this bill and that it be enacted by the Congress.

Sincerely,

WILBUR J. COHEN,
Under Secretary.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE,
Washington, D.C., May 8, 1967.

Hon. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce,
House of Representatives,
Washington, D.C.

DEAR MR. CHAIRMAN: This is in response to your request for a report on the proposed amendments of Mr. Scheuer to H.R. 6430. These amendments would add to the provisions of existing law, relating to applications for grants for projects for university affiliated facilities for the mentally retarded and community mental retardation facilities, a requirement that in developing the plans therefor due consideration be given to excellence of architectural design and to inclusion of works of art.

We would have no objection to the inclusion of these amendments if the committee should want to do so. However, if such amendments are included, we recommend that consideration also be given to inclusion of a similar requirement in the community mental health centers construction program.

We are advised by the Bureau of the Budget that there is no objection to the presentation of this report from the standpoint of the Administration's program.

Sincerely,

WILBUR J. COHEN,
Under Secretary.

Mr. JARMAN. Our first witness this morning will be our colleague from California, the Honorable Jerome Waldie, who has introduced H.R. 5110.

Mr. Waldie, you may proceed as you wish.

STATEMENT OF HON. JEROME R. WALDIE, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. WALDIE. Mr. Chairman, I appreciate the opportunity to appear before your committee so that I may express my interest in

the passage of legislation which will incorporate the provisions of my bill, H.R. 5110.

This bill would authorize a 5-year project grant program to support up to 75 percent of the cost of initiating, extending, or improving services in community mental retardation facilities. My bill specifically provides for additional funds needed to hire the specially trained staffs that are urgently needed throughout the country; and is designed to supplement the efforts of State and community programs, not replace them. It also amends the present law to include the cost of acquiring sites as part of construction costs for community mental health centers and mental retardation facilities.

I am hopeful that this committee will consider favorably the sections of H.R. 5110 which have not been incorporated into H.R. 6430, as I feel that this legislation will substantially assist the mentally retarded toward rehabilitation and so that they may become useful citizens—in many cases self-supporting, and in most instances to be free of the need for expensive institutional care.

My interest in the mental retardation field goes back for many years, including the 8 years I served in the California State Legislature, when I served on the Subcommittee on Mental Health Services of the Assembly Interim Committee on Ways and Means.

I strongly urge that the committee give consideration to the provisions of H.R. 5110, and amend H.R. 6430 to include them.

Mr. JARMAN. Thank you, Mr. Waldie.

We shall hear next from Mr. Carey, of New York, who has introduced H.R. 7688.

STATEMENT OF HON. HUGH L. CAREY, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. CAREY. Mr. Chairman and members of the committee, I appreciate this opportunity to appear before you today in support of my bill, H.R. 7688, which would extend and expand the efforts begun in 1963 initiating Federal support for construction of mental retardation facilities. This program, even now in 1967, is just beginning. The proportions of this problem are, in my opinion, not clearly defined. But even from the viewpoint of what we do know as to the number of persons so unfortunate as to be mentally retarded the conclusion is obvious that we must do more.

This committee conducted lengthy hearings on this problem in 1963 which resulted in the accumulation of a considerable body of information. In the intervening years more information has become available and the many well qualified witnesses who will bring testimony to you will provide an excellent overview of this problem and the services needed to deal with it as effectively as possible.

Rather than being repetitious I would like to deal with one especially difficult and tragic area. I refer specifically to those who are multiple handicapped. By this I mean the child who is both mentally retarded and is deaf, or blind, or has some other handicapping condition. As you can well appreciate, such combination of handicapping conditions makes it extremely difficult to treat either of the conditions—to educate the child. It is imperative that a thorough evaluation of the physical condition preface any treatment procedures. This would make it impossible to avoid one situation reported to me when

a young girl found in a school for the mentally retarded was found to suffer, not from mental disorder, but from deafness. Because she could not hear and because she acted in a manner believed by the non-professional to indicate a retarded condition, this completely inappropriate placement was made.

Let me cite just one more example to illustrate the difficulty of dealing with this complex problem. In this instance the child is both blind and mentally retarded. He is placed in a school for the blind. Now blind children are accustomed to other blind children. But the sometimes more violent physical conduct of that blind mentally retarded youngster brought about disturbances which resulted in severe emotional consequences to his fellow students. He had to be removed from the school for the sake of the other blind students.

This is a terribly serious situation. To the best of my knowledge, the number of children suffering from multiple handicaps is unknown. But, if 3 percent of our population is mentally retarded, as is currently believed to be the case, we are faced with an enormous problem. I urge this committee to act promptly and favorably on the legislation which I have proposed in order that more mental retardation facilities can be constructed and that the vitally needed professional staff can work without further delay.

Mr. JARMAN. Thank you, Mr. Carey. Are there any questions? If not, we shall hear next from Dr. Philip R. Lee, Assistant Secretary of Health and Scientific Affairs, and Dr. William H. Stewart, Surgeon General, Department of Health, Education, and Welfare.

STATEMENT OF DR. PHILIP R. LEE, ASSISTANT SECRETARY OF HEALTH AND SCIENTIFIC AFFAIRS; AND DR. WILLIAM H. STEWART, SURGEON GENERAL, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; ACCOMPANIED BY WALLACE BABINGTON, SPECIAL ASSISTANT TO THE ASSISTANT SECRETARY FOR INDIVIDUAL AND FAMILY SERVICES AND CHAIRMAN OF THE SECRETARY'S COMMITTEE ON MENTAL RETARDATION; AND DR. ROBERT JASLOW, DIRECTOR, DIVISION OF MENTAL RETARDATION, BUREAU OF HEALTH SERVICES, PUBLIC HEALTH SERVICES

Dr. LEE. Mr. Chairman and members of the subcommittee, we are grateful for the opportunity to appear before this subcommittee today in support of H.R. 6430, the Mental Retardation Amendments of 1967, introduced by the chairman of the full committee, Mr. Staggers.

Dr. Stewart and I are accompanied by Mr. Wallace Babington, who is Special Assistant to the Assistant Secretary for Individual and Family Services and Chairman of the Secretary's Committee on Mental Retardation; and Dr. Robert Jaslow, who is Director, Division of Mental Retardation, Bureau of Health Services, in the Public Health Service.

H.R. 6430 would carry out the recommendations made by President Johnson in his February 8 message to the Congress on children and youth. It provides the basis for an intensified national effort to combat mental retardation. This bill would provide, for the first time, Federal support for the initial staffing of community mental retarda-

tion facilities. It would continue the construction programs for university-affiliated and community facilities authorized in legislation recommended by this committee in 1963.

The current mental retardation programs of the Department include support for a variety of professional and technical services related to the improvement and extension of mental retardation programs. These services are offered to States, interested groups, and individuals. During the current fiscal year, over $358 million will be used for the support of mental retardation programs to be carried out by the operating agencies of the Department. (See tables I and II.) These funds will be used for the support of activities such as research, demonstrations, professional preparation, services, and construction. A portion of this amount is used for income maintenance for persons who are mentally retarded.

Dr. Lee. The mental retardation programs of the Department include:

Preventive services designed to reduce the incidence of mental retardation.

Other services which are rendered to or for persons who are mentally retarded. This includes diagnosis and evaluation, vocational rehabilitation, and improved institutional care.

Training programs preparing professional personnel for service and research in the field of mental retardation form an integral part of the Department's total program.

Basic and applied research is supported in the area of health, education, vocational rehabilitation and social services.

Construction programs are providing support for communities and universities in their efforts to expand and improve the training, research, and service activitivies in the field of mental retardation.

Income maintenance programs administered through the social security program and public assistance provide needed support for designed mental retardation beneficiaries.

The administration of mental retardation programs cannot be confined to any one health, education, or welfare area or a single disciplinary group. Since the total program includes a wide range of activities designed to attack problems of mental retardation simultaneously from many vantage points, the responsibility for the various programs has been assigned to those units within the Department that can bring the best professional and technical knowledge and administrative experience to this important new undertaking.

Coordination of the Department's mental retardation programs is accomplished through the Secretary's Committee on Mental Retardation which is a responsibility of the Assistant Secretary for Individual and Family Services. The Secretary's Committee is composed of representatives from all agencies of the Department having programs in the field of mental retardation. These activities are thus administered as a unified, total program which has an object for combating mental retardation with every resource at its disposal. The programs which H.R. 6430 would extend are administered by the Public Health Service. It is my responsibility to work closely with the Surgeon General and the Assistant Secretary for Individual and Family Services to assure the effective implementation of the Department's wide range of mental retardation activities.

In but a few short years we have accomplished much on behalf of the mentally retarded. We have come a long way since President Kennedy's Special Panel on Mental Retardation issued its report in 1962 in which it outlined the scope of the mental retardation problem in this country. In 1963 the Congress responded by enacting two major pieces of legislation in the field of mental retardation: "The Maternal and Child Health and Mental Retardation Planning Amendments of 1963" (Public Law 88–156) and "The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963" (Public Law 88–164).

These two laws have provided the basis for a concerted, national effort to meet the problems of mental retardation. As a result of these and related programs we can report some encouraging progress:

Every State made use of the Federal assistance for planning, and in each State the process of planning for comprehensive mental retardation programs has been completed.

Community and university-affiliated facilities for the mentally retarded are being provided as fast as they can be constructed—over 100 projects for community facilities, and 14 projects for university facilities have been funded to date. These facilities will provide new or improved day care, residential care, and diagnostic and evaluation services for about 35,000 mentally retarded persons.

Grants for the construction of mental retardation research centers during the past year have brought to 11 the total number of such centers now under construction.

More than 14,000 mentally retarded persons were rehabilitated during the past year alone, through grant-in-aid programs of the Vocational Rehabilitation Administration. Projected figures indicate that about 19,000 retardates will be rehabilitated through these programs during the current fiscal year.

Increased Federal support has stimulated State and local governments to initiate a variety of new programs to meet the needs of the retarded at the community level.

In May of 1966 President Johnson established his Committee on Mental Retardation whose functions will be to advise the President concerning the adequacy of present efforts to combat mental retardation and to recommend future action. Secretary Gardner serves as chairman of this Committee.

And, perhaps most important of all, public apathy has turned to growing public awareness and concern for the mentally retarded and their families.

This is all to the good. But we still have a great deal to do. We must do more to reduce or prevent the disabilities associated with mental retardation. Despite the dramatic progress being made in numerous areas of research, we have not learned enough about the fundamental causes of mental retardation. Although we know of some 200 conditions which can result in retardation, we can diagnose the actual cause in only about one-fourth of the patients.

TABLE I.—*Department of Health, Education, and Welfare—Obligations for programs on mental retardation*

Agency and appropriation	1956	1964	1965	1966	1967 estimate	1968 estimate
Office of Education:						
Elementary and secondary education activities	0	0	0	[1] $20,962,742	$26,725,000	$34,750,000
Educational improvement for the handicapped	0	$6,753,364	$7,234,956	8,976,636	10,380,000	[2] 11,548,000
Research and training	0	422,447	566,461	254,960	91,546	26,804
Total, Office of Education	0	7,175,811	7,801,417	30,194,338	37,196,546	46,324,804
Vocational Rehabilitation Administration:						
Grants to States	$375,000	5,500,000	7,500,000	13,764,150	23,104,000	31,080,000
Research and demonstration projects	99,000	2,287,000	3,090,000	3,133,000	3,005,000	2,953,000
Training and traineeships	0	878,000	1,213,000	1,501,000	1,870,000	1,950,000
Special rehabilitation research and training centers	0	0	385,000	500,000	750,000	1,050,000
Innovation grants	0	0	0	225,000	300,000	300,000
Expansion grants	0	0	0	86,500	200,000	300,000
Research and training (special foreign currency program)	0	175,000	93,000	80,000	408,000	
Total, Vocational Rehabilitation Administration	474,000	8,840,000	12,281,000	19,289,650	29,637,000	37,633,000
Public Health Service:						
Community health services	0	2,011,000	9,712,000	28,811,000	43,485,000	42,420,000
Exclusively mental retardation	0	0	(9,712,000)	(28,811,000)	(43,485,000)	(42,420,000)
National Institute of Neurological Diseases and Blindness	919,000	20,376,000	22,636,000	23,808,000	23,861,000	24,867,000
National Institute of Child Health and Human Development	0	5,991,000	7,279,000	8,500,000	12,078,000	20,628,000
Exclusively mental retardation	0	0	(3,642,000)	(5,368,000)	(7,788,000)	(8,496,000)
Grants for construction of health research facilities	0	0	14,745,000	6,234,000	6,026,000	0
Exclusively mental retardation	0	0	(13,740,000)	(6,234,000)	(6,025,000)	0
Mental health research and services	923,000	7,303,000	11,466,000	15,334,000	6,379,000	6,670,000
Exclusively mental retardation	0	0	(8,325,000)	(2,522,000)	(2,528,000)	(4,900,000)
National health statistics	0	10,000	11,000	21,000	21,000	21,000
Total, Public Health Service	1,842,000	35,691,000	65,849,000	82,708,000	91,850,000	94,606,000
Total, exclusively mental retardation	0	0	(35,419,000)	(42,935,000)	(59,826,800)	(55,816,000)

Welfare Administration:						
Bureau of Family Services: [3]						
Grants to States for public assistance	12,000,000	38,000,000	44,000,000	51,000,000	[4] 53,000,000	57,000,000
Salaries and expenses	7,000	25,000	44,000	55,000	65,000	75,000
Children's Bureau:						
Grants for maternal and child welfare	88,000	12,858,000	23,029,000	44,000,000	54,885,000	58,805,000
Salaries and expenses	3,000	330,000	737,000	851,000	969,000	1,025,000
Total, Welfare Administration	12,098,000	51,213,000	67,810,000	95,906,000	108,919,000	116,905,000
Social Security Administration:						
Estimated benefits payments from the trust funds	0	(63,700,000)	(70,900,000)	(84,500,000)	(88,400,000)	(96,200,000)
Trust fund obligations incurred to adjudicate claims of beneficiaries	0	(1,600,000)	(1,900,000)	(1,800,000)	(2,100,000)	(2,100,000)
Total, Social Security Administration	0	(65,300,000)	(72,800,000)	(86,300,000)	(90,500,000)	(98,300,000)
Office of the Secretary:						
Office of General Counsel (legal services)	0	22,000	42,000	42,000	44,000	46,000
Intradepartmental coordination [5]	0	(39,000)	(198,000)	(238,000)	(105,000)	(105,000)
President's Committee on Mental Retardation	0	0	0	0	[5] (158,000)	[6] 597,000
Grand total, general funds	14,414,000	102,941,811	153,783,417	228,139,988	267,646,546	296,111,804
Grand total, trust funds	0	65,300,000	72,800,000	86,300,000	90,500,000	98,300,000
Grand total, all funds	14,414,000	168,241,811	226,583,417	314,439,988	358,146,546	394,411,804

[1] Estimated.

[2] Not including funds authorized under title VI of Public Law 89-10 as amended by Public Law 89-750.

[3] Exact information is not available on the costs due to mentally retarded people who are receiving public assistance because data secured does not single out this 1 cause as a factor of disability or dependency. However, it is known that mental retardation is an important cause of disability for those receiving aid to the permanently and totally disabled under the Federal-State public assistance program. The amounts shown here are estimates based on a constant percentage of total payments under this part of the program.

[4] Includes funds from proposed supplemental for public assistance grants for 1967.

[5] Shown as nonadd items since they were derived from funds available to other agencies for mental retardation activities.

[6] Beginning in 1968, this item is included in direct funding as a part of the account "Mental health research and services."

TABLE II.—*Department of Health, Education, and Welfare—Obligations for mental retardation programs, by activity, agency, and appropriation designation, fiscal years 1965–68*

[In thousands of dollars]

Agency and appropriation	Fiscal year			
	1965 actual	1966 actual	1967 estimate	1968 estimate
PREVENTIVE SERVICES				
Welfare Administration: Grants for maternal and child welfare	9,528	24,156	30,000	30,000
Total, preventive services	9,528	24,156	30,000	30,000
OTHER SERVICES				
Office of Education: Elementary and secondary education activities	----------	[1] 20,963	26,725	34,750
Vocational Rehabilitation Administration:				
Grants to States	7,500	13,764	23,104	31,080
Research and demonstration projects	1,357	----------	----------	----------
Innovation grants	----------	225	300	300
Expansion grants	----------	86	200	300
Total, Vocational Rehabilitation Administration	8,857	14,075	23,604	31,680
Public Health Service: Community health services	628	2,230	3,228	3,275
Welfare Administration:				
Grants for maternal and child welfare	8,892	11,220	11,000	11,000
Salaries and expenses	630	664	747	775
Total, Welfare Administration	9,522	11,884	11,747	11,775
Total, other services	19,007	49,152	65,304	81,480
PROFESSIONAL PREPARATION				
Office of Education:				
Educational improvements for the handicapped	6,570	7,657	9,000	[2] 9,000
Research and training	212	----------	----------	----------
Total, Office of Education	6,782	7,657	9,000	9,000
Vocational Rehabilitation Administration: Training and traineeships	1,213	1,501	1,870	1,950
Public Health Service:				
Mental health research and services	2,981	3,184	1,289	1,674
Neurology and blindness activities	8,622	9,208	9,500	9,800
Child health and human development	682	752	1,109	1,982
Community health services	425	2,782	2,704	2,725
Total, Public Health Service	12,710	15,926	14,602	16,181
Welfare Administration:				
Grants for maternal and child welfare	3,147	5,865	10,085	12,865
Salaries and expenses	40	64	100	100
Total, Welfare Administration	3,187	5,929	10,185	12,965
Total, professional preparation	23,892	31,013	35,657	40,096
RESEARCH				
Office of Education:				
Educational improvements for the handicapped	665	1,320	1,380	[2] 2,548
Research and training	354	255	92	27
Total, Office of Education	1,019	1,575	1,472	2,575
Vocational Rehabilitation Administration:				
Research and demonstration projects	1,733	3,133	3,005	2,953
Special rehabilitation research and training centers	385	500	750	1,050
Research and training (special foreign currency program)	93	80	408	----------
Total, Vocational Rehabilitation Administration	2,211	3,713	4,163	4,003
Public Health Service:				
Mental health research and services	8,425	12,095	5,039	4,946
Neurology and blindness activities	14,014	14,600	14,361	15,067
Child health and human development	6,597	7,748	10,969	18,646
Community health services	91	48	257	630
National health statistics	11	21	21	21
Total, Public Health Service	29,138	34,512	30,647	29,310

See footnotes at end of table, p. 15.

TABLE II.—*Department of Health, Education, and Welfare—Obligations for mental retardation programs, by activity, agency, and appropriation designation, fiscal years 1965–68*—Continued

[In thousands of dollars]

Agency and appropriation	Fiscal year			
	1965 actual	1966 actual	1967 estimate	1968 estimate
Welfare Administration:				
Grants for maternal and child welfare	1,462	2,759	3,800	4,940
Salaries and expenses	67	123	122	150
Total, Welfare Administration	1,529	2,882	3,992	5,090
Total, research	33,897	42,682	40,204	50,978
CONSTRUCTION				
Public Health Service:				
Community health services	7,223	20,562	32,810	34,500
Grants for construction of health research facilities	14,745	6,234	6,026	
Total, Public Health Service	21,968	26,796	38,836	34,500
Total, construction	21,968	26,796	38,836	34,500
PLANNING				
Public Health Service:				
Community health services	1,060	2,156	3,420	50
Total, planning	1,060	2,156	3,420	50
INCOME MAINTENANCE				
Social Security Administration:				
Estimated benefit payments from trust funds	70,900	84,500	88,400	96,200
Trust fund obligations incurred to adjudicate claims of beneficiaries	1,900	1,800	2,100	2,100
Total, Social Security Administration (trust funds)	72,800	86,300	90,500	98,300
Welfare Administration:				
Grants to States for public assistance [3]	44,000	51,000	[4] 53,000	57,000
Salaries and expenses	44	55	65	75
Total, Welfare Administration	44,044	51,055	53,065	57,075
Total, income maintenance	116,844	137,355	143,565	155,375
OTHER				
Public Health Service:				
Mental health research and services	60	55	51	50
Community health services	285	1,033	1,066	1,240
Total, Public Health Service	345	1,088	1,117	1,290
Office of the General Counsel (legal services)	42	42	44	46
Total, other	387	1,130	1,161	1,336
Interdepartmental coordination [5]	(198)	(238)	(105)	(105)
President's Committee on Mental Retardation			[5] (158)	[6] 597
Grand total, all funds	226,583	314,440	358,147	394,412
Grants and services	109,739	177,085	214,582	239,037
Income maintenance payments	116,844	137,355	143,565	155,375

[1] Estimated.

[2] Not including funds authorized under title VI of Public Law 89-10 as amended by Public Law 89-750.

[3] Exact information is not available on the costs due to mentally retarded people who are receiving public assistance because data secured does not single out this one cause as a factor of disability or dependency. However it is known that mental retardation is an important cause of disability for those receiving aid to the permanently and totally disabled under the Federal-State public assistance program. The amounts shown here are estimates based on a constant percentage of total payments under this part of the program.

[4] Includes funds from proposed supplemental for public assistance grants for 1967.

[5] Shown as nonadd items since they were derived from funds available to other agencies for mental retardation activities.

[6] Beginning in 1968, this item is included in direct funding as a part of the account "Mental health research and services."

Good prenatal and maternity care including family planning services especially when provided to women in the highest risk groups—generally the poorest, in socioeconomic terms—can do much to reduce the incidence of mental retardation. The prevention, correction, or treatment of nutritional or health defects prior to, or between, pregnancies is one of the most important things that can be done to prevent mental retardation. The social and environmental factors are also important—mental retardation is not solely a medical problem. But even as we work in these and other ways to reduce the incidence of potential retardation, we must recognize that improvements in medical care are saving and prolonging the lives of many retarded children who would otherwise not have lived. This is not unfamiliar—the same is true with respect to the aged: new problems must be faced as we conquer disease, and succeed in lengthening the lifespan.

On balance, despite these advances we do not anticipate any immediate or substantial reduction in the number of families who each year bear the burden of mental retardation. We can hope to prevent many cases of retardation, and to ameliorate its effects in many more. We can make it possible for a much larger number of the retarded to live with some degree of decency and normalcy in our society.

Today, even the most optimistic observers concur in the view that services for the mentally retarded will not keep pace with the demand for many years to come. The waiting lines are tragically long and we have not yet begun to provide services to all those in need.

Over 189,000 mentally retarded persons are in institutions, and roughly 31,000 are on official waiting lists to get into the institutions but cannot be admitted because of lack of available facilities and services. We believe that many more who do not appear on the official lists are also waiting for institutional services, and a far greater number who live in the community and who urgently need help either in the form of diagnostic or clinical care, or special education, training, and other services.

Many of the retarded have the potential to improve their intellectual and social abilities and to make meaningful contributions to society. Many are able to benefit from programs of education, training, and vocational rehabilitation and can be expected to enter the labor market and to become at least partially self-supporting after completion of their training. All of them should be given the chance to live as happily and as productively as possible.

Mr. Chairman, today we ask your consideration and support to continue and enlarge upon the commitment we undertook in 1963.

Construction grants. Under the existing authority in title I of the Mental Retardation Facilities Construction Act of 1963—Public Law 88–164—grants are awarded for the construction of both university-affiliated and community facilities. The authorizations under Public Law 88–164 for the university-affiliated facilities construction program will expire June 30 of this year—just a few months from now. The extension of this program and of the community facility program contained in H.R. 6430 would assure continuity of Federal financial assistance to help meet the many unfulfilled needs of the Nation's mentally retarded.

University-affiliated facilities. To date, a total of 17 projects grants for university-affiliated facilities have been approved for funding, and

14 of these have actually been funded. These clinical facilities are designed to serve as training centers for much-needed professional personnel. They provide training in a broad, demonstration setting in which a full range of inpatient and outpatient services is available. The total construction cost of the 14 projects funded since the beginning of the program is $42 million, with a total Federal share of $30 million. In the 14 university-affiliated facilities already funded, nearly 10,000 professionals each year will receive training in medical, education, and other disciplines related to the prevention and treatment of mental retardation.

The proposed bill would extend the university-affiliated construction program for 5 years, with an authorization of $10 million for fiscal year 1968, and for such sums as they may be necessary for the 4 succeeding fiscal years.

The facilities funded or approved for funding to date represent only a fraction of the total number of colleges and universities which desire assistance for mental retardation facilities. More than 100 universities and colleges have expressed interest in participating, and 43 are actively planning programs at this time. Without Federal financial assistance few, if any, universities are able to defray the large construction costs involved.

The best planning and the most faithful implementation of plans by the States cannot succeed without manpower—the properly trained, skilled, and knowledgeable professional is an extremely vital part of the total program—and he is in short supply. Few medical schools, colleges, or universities presently have the specialized facilities needed for proper programs of training in the complex problems of mental retardation. The university-affiliated facilities will provide interdisciplinary training for the many professionals and technicians we need.

Section 2(b) of the proposed legislation makes two changes in the existing provision relating to university-affiliated facilities. First, it would authorize services to persons with "other neurological handicapping conditions found by the Secretary to be sufficiently related to mental retardation to warrent inclusion" under the university-affiliated program. This will make it possible to broaden the training offered in the facilities, so that the personnel being trained can be exposed to and learn to deal with the many persons with neurological handicapping conditions related to retardation who require treatment, training, education, psychological and rehabilitative services similar to those provided the mentally retarded. Examples of such conditions are communication disorders—speech, vision, hearing—and neuromuscular conditions—cerebral palsy. Second, it would allow a portion of a university-affiliated facility project to be planned and utilized for research activities incidental or related to the purposes spelled out in existing law. This will help to assure a continuing and well-directed research effort to expand our knowledge of mental retardation.

On the basis of the overwhelming interest expressed by these educational institutions, the need for trained manpower, and for continued research, we ask that the Congress extend this program as provided in H.R. 6430.

Community facilities. H.R. 6430 would also extend the community facilities program for 4 years, retaining the present authorization of

$30 million for fiscal year 1968, and authorizing such sums as may be necessary for the 4 succeeding fiscal years.

Since the beginning of the program in 1963, more than 100 construction projects for community facilities have been funded. The total construction cost of these facilities is $100 million; the Federal share is $20 million.

The prime responsibility for the care and treatment of the mentally retarded rests with the States, with local communities, and with the families of the retarded. The funds available under this program are allotted among the States on the basis of population, financial need, and the need for facilities for the mentally retarded. The States set the priorities among the projects competing for approval. The competition is strong, and it will intensify. There is a backlog of unmet needs and large gaps in services for the mentally retarded. No service for the mentally retarded has yet been inaugurated in any community and found itself with a shortage of clients once the availability of the program was known. The number of mentally retarded persons now known to all agencies suggests that the continued demand and need for services will exceed the availability of such services for many years to come.

These community facilities will provide a wide variety of services, although not the same range of services in every instance. Projects already funded will provide diagnostic and evaluation services, residential care, specialized clinical care, vocational rehabilitation, training, and social services.

For example, the Paul Valley State School in Oklahoma added diagnostic and evaluation services for a 35-county area to aid welfare agencies, health departments, community agencies, and family physicians both to understand the needs of the retarded and to plan treatment programs suited to their potential.

In Miami, the Sunland Training Center added diagnostic and evaluation services and day care and residential facilities to offer a wide range of care to patients whose conditions vary from the moderately retarded to those requiring 24-hour nursing care. Over 1,000 additional retarded are being served by expansion of the program.

These community facilities are where the work will be done, to the extent that it can be done; where hope and help will be given, to the extent we can give them.

Staffing of community mental retardation facilities. Section 4 of the proposed legislation would add a new program of project grants to assist communities in the establishment of facilities for the mentally retarded by helping them meet a portion of the costs of professional and technical personnel needed for initial operation of new facilities, or for providing new services in existing facilities for the mentally retarded. Federal funds would be used to supplement and increase, to the extent practicable, the level of State, local, and other non-Federal funds for mental retardation services.

This new program would provide for declining Federal participation—patterned on the mental health staffing provisions considered by this committee in recent weeks. Over a period of 4 years and 3 months the Federal share would be reduced from 75 percent for the first 15 months to 60 percent for the next year, to 45 percent for the next year, and finally to 30 percent for the last year.

Our desire is not to supplant local effort or stifle local initiative. Our expectation here, just as with the community mental health centers, is that community participation can and will gradually furnish the necessary long-run support for these facilities.

To provide the continum of services necessary to make real gains in the treatment and rehabilitation of the retarded, the community mental retardation facilities must be adequately staffed. Present data indicate that a large portion of the operating expenses of a community mental retardation facility represents staffing costs. Without adequate funds, community facilities can neither provide the urgently needed services to the mentally retarded nor possibly attract more professionals to this field.

The staffing grant authority will help overcome the critical shortage of competent, professional help and will thereby make the delivery of the entire range of mental retardation services a reality—not just a hope. This bill would authorize $7 million for fiscal year 1968, and such sums as may be necessary for 4 succeeding fiscal years for initial grants. The bill further authorizes such sums as may be necessary to enable the Secretary to make grants for the fiscal year 1969 and each of the next 7 years, for continuation of grants.

In 1963, this committee and the Congress gave tangible evidence of our concern in enacting the mental retardation facilities legislation. Nothing has happened to cause us to doubt the wisdom of that judgment. We ask now that you reaffirm it.

Thank you for allowing me to appear before you today to testify on H.R. 6430. If you have any questions, Dr. Stewart, Mr. Babington, Dr. Jaslow, and myself would, of course, try to answer them.

Mr. JARMAN. Thank you very much, Dr. Lee.

As I understand it the bill requests authorizations for funds for fiscal year 1968 on existing programs that are the same as the prefiscal year?

Dr. LEE. Yes, sir.

Mr. JARMAN. Would the Department furnish the subcommittee with the figures for the other years that are requested? It is an open end request at the present time.

Dr. LEE. We will be pleased to submit our estimates, Mr. Chairman.

(The information requested follows:)

TABLE III.—*Facilities for the mentally retarded—H.R. 6430 estimates for 5 years of authorizations*

	Fiscal year 1968	Fiscal year 1969	Fiscal year 1970	Fiscal year 1971	Fiscal year 1972	Fiscal year 1973	Fiscal year 1974	Fiscal year 1975	Cumulative total
University affiliated construction program:									
New obligational authority	$10,000,000	$20,000,000	$20,000,000	$20,000,000	$20,000,000				$90,000,000
Number of grants	(3)	(5)	(5)	(5)	(5)				(23)
Community facility construction:									
New obligational authority	[1]	30,000,000	50,000,000	50,000,000	50,000,000				180,000,000
Number of grants		(182)	(235)	(235)	(235)				(887)
Staffing: [2]									
Total:									
Dollars	7,000,000	15,600,000	26,200,000	40,000,000	54,400,000	$38,400,000	$23,600,000	$10,400,000	215,600,000
Number of grants	(58)	(141)	(258)	(425)	(584)	(501)	(384)	(217)	(2568)
New grants:									
Dollars	7,000,000	10,000,000	14,000,000	20,000,000	26,000,000				77,000,000
Number of grants	(58)	(83)	(117)	(167)	(217)				(642)
Continuations:									
Dollars		5,600,000	12,200,000	20,000,000	28,400,000	38,400,000	23,600,000	10,400,000	138,600,000
Number of grants		(58)	(141)	(258)	(367)	(501)	(384)	(217)	(1926)
New obligational authority	7,000,000	10,000,000	14,000,000	20,000,000	26,000,000				77,000,000
Total program:									
Dollars	17,000,000	65,600,000	96,200,000	110,000,000	124,400,000	38,400,000	23,600,000	10,400,000	485,600,000
Number of grants	(61)	(328)	(498)	(665)	(824)	(501)	(384)	(217)	(3478)

[1] The sum of $15,000,000 is requested in 1968 under existing obligational authority.
[2] Estimates include amounts for initial and continuation grants under proposed legislation which authorizes initial grants totaling $7,000,000 in fiscal year 1968 and continuation grants following on initial grants made in fiscal years 1968 through 1972.

Mr. JARMAN. One question that I thought might be helpful for the record, would you give the subcommittee a progress report on the programs of construction of centers for research of mental retardation under section 761 through 766 of the Public Health Services Act? I ask this because I note that this program is not scheduled for extension under the bill.

(The information requested appears on p. 29.)

Dr. LEE. Dr. Stewart would you?

Dr. STEWART. If you recall Mr. Jarman when that legislation was before you we talked about the need for around eight research centers in the country which would conduct programs aimed at the problem of the etiology of mental retardation and the treatment of mental retardation. There are actually 12 such research centers at universities in various parts of the country so I think we have carried out the intention that was talked about at that time. We now have underway the construction and implementation of these 12 such centers.

Dr. LEE. The first one of these goes into operation this spring in May or June.

Dr. STEWART. The first one will be in operation this spring, yes.

Mr. JARMAN. Thank you very much. Mr. Nelsen.

Mr. NELSEN. I am interested in a progress report by States. Now, realize that one of the very, very definite needs is in the field of training personnel that could adequately staff community health centers, is that not true?

Dr. STEWART. That is correct.

Mr. NELSEN. That is one of the real needs and real difficulties. Now under the laws passed by the Congress there has been money allocated for day care centers has there not?

Dr. STEWART. Yes.

Mr. NELSEN. The decision rests with the State, does it not, as to where the Federal money will go?

Dr. STEWART. Mr. Nelsen, the decisionmaking as to where the money goes or where the facility will be constructed under the program of community facilities for the mentally retarded rests with the State.

Mr. NELSEN. Exactly. That is the point I wanted to make. The attention also seems to be for construction for new facilities, bricks, mortar, and new facilities. My experience has been that there are facilities available for a very minimal cost and we have tried, in some cases, to get some help in the way of making playgrounds available and improving an existing building. We have not been able to get anything moving and have had to collect money locally to do the job. I am trying to put my finger on where the problem has been and why we have been unable to move.

We have two day care centers for the retarded in my district. One is in Cottonwood County which has been funded by the poverty program and they are doing a very fine job. The other is located at Biscay in McLeod County and uses, the little brick four-room schoolhouse I have often referred to. It needed some improvement in the way of fencing around the yard to prevent youngsters from getting out on the highway, but this had to be done with local funds. Now an application has been filed to have this Biscay center approved as a demonstration center. Even if approved, this assistance would have

limited longevity and would finally phase out. Then we would have to support it locally.

I would like again to emphasize the need for getting help to some of these centers. We can build community centers and geographically they must be located so they are accessible all over the country. We have country schoolhouses all over the United States that have been vacated by reorganization, and these could be taken over for practically nothing. I am interested in pursuing this possibility, and our committee was interested in developing this idea. I remember Congressman O'Brien of New York felt that this was a real good idea, yet we have been unable to get it moving. I wonder if it was our fault or whose fault it was.

Dr. STEWART. No, sir. I do not think it is anybody's fault. You will recall that under Public Law 88–156 funds were provided to the States for developing a mental retardation plan. This has been completed and all the States have plans. Under the plan they looked at the needs and the resources available and began to set up priorities within their States to determine where they should put the money that is allocated for the construction of facilities. They set these priorities within the provisions of the State plan.

There is such need, such a backlog of need in all States, that I am sure that what they are trying to do is provide funds for the biggest impact at the present time. As we begin to plan inroads into this backlog I think the States will be able to expand their attempts at construction within their own priorities.

Now the emphasis is on new facilities, but many times this new facility is one which has been added on to an existing one. We are trying to develop more services for more mentally retarded.

Mr. NELSEN. The problem seems to be staffing. That is our real heavy expense item and in many cases it requires almost as many in number of staff as we have youngsters in the school, depending on their condition. I am very hopeful that we could get some geographically located center for the retarded because I am a real liberal in that area. We are dealing with people who are not equipped to compete with those of us who have our faculties and I think there is much to be done in this area.

Dr. STEWART. You are quite right Mr. Nelsen. Staffing is a real problem for all communities to face. We have found in some instances that States have set a priority on a construction project but because we have required that they demonstrate a capability for operating the facility after they have constructed it, they have had to skip around on the priority list. Because a particular community which had a high priority construction project could not fund the staffing of the facility, they had to go to another one that could fund it, although in terms of need it could have been a high priority on the State's list. This has been a major stumbling block in terms of efficient geographical distribution.

Mr. NELSEN. I do not want to discourage the idea of giving to the States the decisionmaking as to priority and administration. I realize that if the Federal Government moves in too forceably then the States loose the opportunity of determining where the needs are. This they should know much better than we would from this level, so I am not in agreement with any attempt at greater centralization.

Dr. LEE. One other thing on the problem you addressed yourself to, is the fact that the law does not permit acquisition of facilities and I think this would apply in some of these circumstances that you mentioned. This has been a limitation in the minds of some people to meet other priorities.

Mr. NELSEN. Of course, the facilities I am talking about can be purchased for $1 so there is no great cost item involved. Most of these school buildings are standing vacant. They would almost be a gift and they could be selected where school district boundaries are not taken into consideration. Mainly geographic locations would be considered in making available facilities for the people that you want to help.

Dr. LEE. They are in the community where they are geographically appropriate.

Mr. NELSEN. Thank you. No more questions.

Mr. JARMAN. Doctor, have you any way of estimating accurately how many mentally retarded people there are in the country? I know you have referred to the fact.

Dr. STEWART. No. We do not have an accurate estimate. The figure of 6 million is used and I think this is as good a figure as we can get at the present time. These 6 million are the lowest 3 percent of our population in figures of IQ. Now, we do have a breakdown of the distribution of the retarded within that 6 million. If I may, I will show you a pie diagram (fig. 1) which shows that.

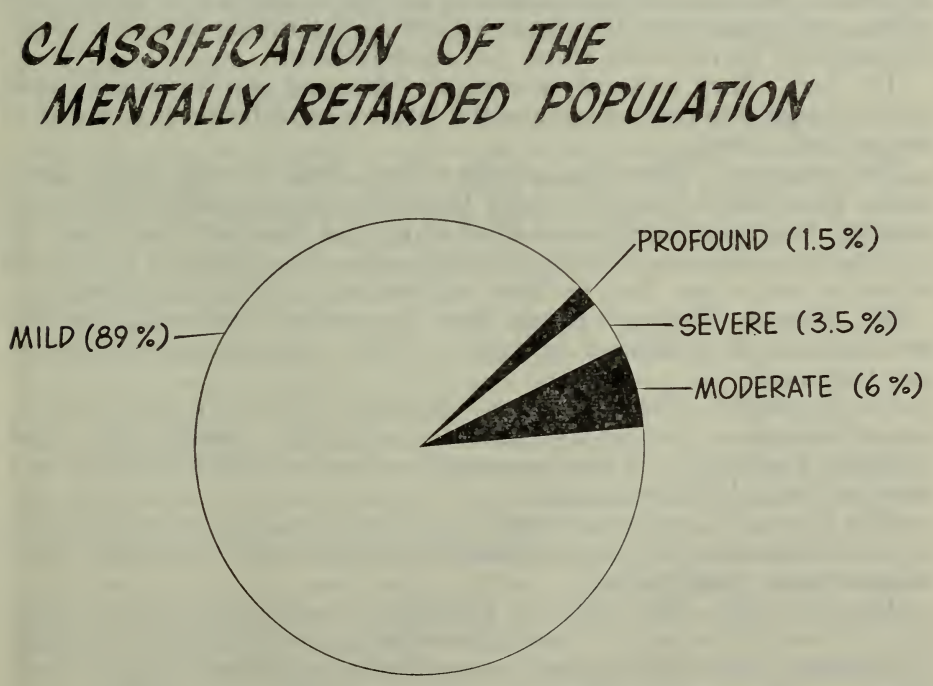

FIGURE 1

Mr. JARMAN. Yes.

Dr. STEWART. This is the 6 million range, of course. The bulk of them are mildly retarded. In this group you have people who need some assistance. In here are also those characterized by depression of IQ which results from cultural deprivation and other factors. You have about 1.5 percent who are profoundly retarded. These are people who would require almost constant attendance. They may be ambulatory but that is about the limit of their capabilities. Severely retarded represent three and a half percent, and the moderately retarded, 6 percent.

Now these people about in here, many of the severely and profoundly retarded are the ones you will find in the institutions and they fluctuate between these categories depending on whether they have a combination of other things with their mental retardation.

Mr. BROWN. Meaning?

Dr. STEWART. Pardon me?

Mr. BROWN. Meaning what?

Dr. STEWART. A person with cerebral palsy may be mentally retarded too and if they have a combination even though their retardation may be moderate, they may require institutional care. There are other combinations of this type too.

Mr. BROWN. If I may, in the mild 89 percent, am I to infer from what you said that this is a curable condition?

Dr. STEWART. Well, there is some evidence that you can raise the IQ with special attention to cultural problems, education, this sort of thing. And some near the upper ranges of the mildly retarded might successfully be removed from this classification.

Dr. LEE. They certainly are employable and can be rehabilitated even though you cannot reverse the level of retardation if it is due to some birth defect.

Dr. STEWART. There are people whose level of retardation needs to be identified because in order to fit into a meaningful life in our society, they may need some kind of special training which may be nothing more than a little more attention in education or a little more attention as to how they go from training into job opportunities.

Mr. BROWN. They are people then who are just culturally deprived or deprived of education because of their economic circumstances, are they not?

Dr. STEWART. That is correct. However, there are persons who are classified in the mildly retarded group for reasons other than cultural deprivation. There are people who are mildly retarded as a result of organic disturbances.

Mr. BROWN. I just want to get this clear in my own mind. The field does include those who are culturally deprived and were deprived of educational opportunities?

Dr. STEWART. The field, by definition, is a range of IQ's within this. There will be people who are there because of cultural deprivation, including all the factors that you mentioned, social-economic factors. There may be people in this range who are mildly retarded because of an organic disturbance. Many may be mildly retarded as a result of having had measles or because of oxygen lack at or during birth or any of the multiplicity of 200 causes that we have identified. Retardation is a mixture as you move down into the profound.

Mr. BROWN. Well, in the moderate, is there cultural deprivation in those who are moderately retarded?

Dr. STEWART. Yes; there are some, but you are moving closer to the group who are most likely to have some kind of brain damage.

Dr. LEE. This is a field where we are just beginning to study and understand some of the problems related to sensory deprivation and other factors in infancy that can lead to mental retardation. For example, the child who grows up in a home where there is lack of usual communications, lack of a variety of visual or verbal stimuli the youngster who is often left alone for long periods—we are just beginning to understand these problems through current research being done.

Mr. BROWN. There really may be no good way to ask this question, but in the 89 percent of mildly mentally retarded is there any significant percentage of those who are capable of being completely returned to full or average IQ status?

Dr. STEWART. Well, they are quite capable of being useful——

Mr. BROWN. Is there any limit? Is there any limit to which their IQ can be raised by training? That is the question, I guess.

Dr. STEWART. This I do not know. There can be variation in IQ. There can be changes brought about in IQ by certain effects on them. What the range of that is I do not know, but I would assume there is some kind of upper range on it. I think more important is the idea that within that mild group is the substantial proportion of people who can, with a certain amount of assistance and with a wide variety of types of services, be made useful citizens participating in society as ordinary people.

Mr. BROWN. Independent?

Dr. STEWART. Self-supporting. Independent, that is correct.

Mr. JARMAN. One thing I might ask, in the testimony that we heard a few days ago on the mental health centers bill a projection was indicated that the objective would be 2,000 of the centers by 1980. In this field of mental retardation, are you in a position to make a long-range projection on what you think the country's need will be and what the objectives will be?

Dr. STEWART. I think it is difficult to compare the two, Mr. Chairman. The concept of the community mental health center was that it be a combination of functions which may be located in one place or maybe contiguous places to which you could travel back and forth. Mentally ill people are more likely to use the range of these four to six basic services we are talking about. In the mental retardation area you are talking about a very broad scope of types of services which may be located in many many different places. And you almost have to have an individual plan for each mentally retarded person. Therefore, there is no real center. What we are talking about under this bill is helping the community increase the scope of services needed to handle the mentally retarded.

If I may, I will show you another chart (fig. 2) that I think will illustrate this.

SPECIALIZED SERVICES NEEDED BY THE MENTALLY RETARDED

	EDUCATION	VOCATIONAL	TRAINING	DIAGNOSIS AND EVALUATION	TREATMENT	RESIDENTIAL	DAY CARE
	Academic Pre-school Post-school	Work Evaluation Work Adjustment Training Vocational Training Sheltered Workshop Terminal Workshop Job Placement	Motor Skills Activities of Daily Living Occupational Training Personality Development Social Development	Diagnosis Assessment Reassessment Referral Lifetime planning Treatment (short-term) planning	Physical Psychological Social	Short-term Long-term Group homes Halfway Houses	Supportive Therapeutic Recreation Pre-school
PROFOUND (1.5%)							
SEVERE (3.5%)							
MODERATE (6%)							
MILD (89%)							

FIGURE 2

Mr. JARMAN. Yes, please.

Dr. STEWART. This tremendous range of services is about the best way I know to show it. Here you are talking about educational, vocational training, diagnostic evaluation, treatment, residential, day care, a whole range of different kinds of services that are needed for the mentally retarded under this bill. We may be building a facility for diagnostic and evaluation or we may be adding to a residential or a combination, but to put all of these into one facility as a center would be rather unrealistic. Most communities have a piece of this range of services. I recall an application from Florida, there have been about five grants I believe, one providing diagnostic and evaluation, one providing day care, one as a combination of the three areas. This is why I think it is a different concept from that of the community mental health center and it is difficult to say how many construction grants we would make. We cannot determine the nature of a center as such. We did this in the Department of Mental Health because each center is calculated to serve a population size and by dividing into the population of the United States I can come up with a number which is a target for it.

Dr. LEE. We would have to estimate the number of projects, but as Dr. Stewart has already pointed out, it is not comparable to the projects funded in mental health center program.

Mr. JARMAN. As you brought out in your statement you are adhering to the objective of local responsibility and local efforts with the Federal Government coming in aiding in the overall?

Dr. LEE. Yes, sir.

Mr. JARMAN. Mr. Rogers.

Mr. ROGERS. Thank you, Mr. Chairman. There are a few questions I have. What about your university-affiliated programs or construction programs; do you plan also to staff these university-affiliated programs?

Dr. LEE. The funds for staffing those, Mr. Rogers, come from a number of sources. The Childrens' Bureau administers a program which is providing funds to aid in the training of staff for the university-affiliated programs. Also, the Public Health Service, through the National Institute of Neurological Diseases and Blindness, and the Institute of Child Health and Human Development, and the Vocational Rehabilitation Administration all can contribute funds which would help to support staffing.

Mr. ROGERS. Do you plan to staff them under the provisions of this legislation?

Dr. LEE. No, sir. The funds for staffing depend on whether a project involves rehabilitation, research, or training. The funds would come from one, or more, of these separate sources.

Mr. ROGERS. How much money would be going into staffing the university-affiliated centers?

A rough figure.

Mr. BABINGTON. From 50 to 80 percent of the cost of construction. We do have some estimates that we could submit for the record.

Mr. ROGERS. Excuse me, I did not understand. This is for staffing?

Mr. BABINGTON. For operation.

Mr. ROGERS. You are funding from 50 to 80 percent?

Mr. BABINGTON. This would be the cost of operating the university-affiliated, it can run from 50 to 80 percent of the cost of construction. Now, we are not——

Dr. STEWART. I do not think that answers your question, Mr. Rogers. What you want is the proportion of operational funds of university-affiliated centers that may be Federal money from various programs.

Mr. ROGERS. Yes. How much are we spending or putting into it?

Dr. STEWART. None are in operation at the present time.

Mr. ROGERS. None in operation?

Dr. LEE. The authorization for this purpose in the Childrens' Bureau program is $4 million this year.

Mr. BABINGTON. $4 million this year and $7 million requested for next year.

Mr. ROGERS. For staffing?

Dr. LEE. For training of personnel which would work in these university centers.

Mr. ROGERS. When will we get one of these functioning?

Mr. BABINGTON. The first one is due in June of this year.

Mr. ROGERS. In June the first one? We passed this when, in 1963?

Dr. STEWART. That is correct.

Mr. ROGERS. We are just now getting the first one underway?

Dr. LEE. That is correct. The plans which must precede construction and operation of a university-affiliated facility are complex. It involves not just construction but plans for training and services——

Mr. ROGERS. Now, where will this be. Where will this first one be?

Dr. LEE. The Children's Hospital Institute in Maryland.

Mr. ROGERS. In Maryland? Where is that located?

Mr. BABINGTON. Reisterstown, Md.

Mr. ROGERS. Is that a university?

Mr. BABINGTON. University-affiliated.

Mr. ROGERS. What university?

Dr. LEE. Johns Hopkins University.

Mr. ROGERS. How far from Baltimore? Is it close or——

Dr. JASLOW. Fairly close. I do not know the exact distance.

Mr. ROGERS. It is not right in the same town?

Dr. JASLOW. No. sir.

Mr. ROGERS. How did you mean the university-affiliated when you presented it to us? I thought you were going to have it right at the facility with the university. This was the idea, that the staff was going to work right there.

Dr. LEE. Many teaching hospitals are affiliated with medical schools. For example, seven teaching hospitals in Boston are affiliated with Harvard Medical School. These hospitals are not all near the medical school, they are all over town.

Mr. ROGERS. I can see in the same town, but I did not think that it was going to be outside.

Dr. LEE. There are a number of medical schools with affiliated hospitals that are not located in the same town. For example, Stanford Medical School has two affiliated hospitals; one is 14 miles and the other is 7 or 8 miles from the university and they run major teaching programs in these hospitals with a full-time faculty from the medical school.

Mr. ROGERS. I recall the presentation when we passed this. You envisioned that they would bring children in here, and there would be new ways of treatment along with the research. It was not just train-

ing, but training would also be a byproduct and I had envisioned that it would be right within the university proper as a very major part of it.

Dr. LEE. Well, I think that some of them very definitely will be an integral part of a university center.

Mr. ROGERS. Do we have any plans for those?

Dr. LEE. There are a number of university-affiliated facilities that have been approved. We can submit this list.

(The information requested follows:)

PROGRESS REPORT ON MENTAL RETARDATION RESEARCH CENTERS AND UNIVERSITY-AFFILIATED FACILITIES

MENTAL RETARDATION RESEARCH CENTERS

One of the programs authorized in P.L. 88–164, "Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963," is the construction of centers for research on mental retardation and human development. The grants available under this program are designed "to assist in meeting the cost of construction of facilities for research, or research and related purposes, relating to human development, whether biological, medical, social, or behavioral, which may assist in finding the causes, and means of prevention, of mental retardation, or in finding means of ameliorating the effects of mental retardation."

A total of $26 million has been authorized for this program over a four-year period beginning in fiscal year 1964. As of January 1967, eleven grants have been awarded. The following summary descriptions indicate the types of centers and programs supported by these grants.

This program is administered by the National Institute of Child Health and Human Development, Public Health Service, Department of Health, Education, and Welfare.

University of Washington, Seattle, Washington

The Mental Retardation Program at the University of Washington is a multi-disciplinary university-wide endeavor involving the Medical School, Dental School, School of Nursing, School of Social Work, the College of Education and the Departments of Psychology and Sociology.

Research in the biological sciences will include developmental biology, perinatal biology and the neurological sciences. Behavioral studies will include individual behavior under carefully controlled environmental conditions, family and peer group interactions, and applied research on testing of educational and treatment techniques. The facility will also be utilized for research on new methods and materials for the retarded.

This Center will feature outpatient and residential facilities for comprehensive clinical studies of retarded children and will provide research training programs to prepare physicians and professionals in the health related disciplines for research in mental retardation and related aspects of human development.

Total cost of project: $8,290,970.
Federal Share: $5,700,000.
Date of Award: October, 1964.
Estimated completion date: 1969.

Albert Einstein College of Medicine, Yeshiva University, New York, New York

This Program will be a joint effort of the Departments of Obstetrics and Gynecology, Pediatrics and Psychiatry. It will concern itself with research problems involving the total human organism, the family and the community with special emphasis on factors leading to mental retardation. Studies in developmental biology will be conducted at all levels, including molecular and enzymatic studies of the organ systems. Research will also be undertaken in the behavioral and social sciences and ecology.

The College of Medicine has working arrangements with the Edenwald School, a residential treatment center for retarded children, and with the New York City Hospital which will enable them to translate new research findings into patient care.

Total cost of project: $5,124,815.
Federal Share: $3,085,000.
Date of Award: October, 1964.
Estimated completion date: 1968.

Children's Hospital, Cincinnati, Ohio

This Research Center will focus on biomedical research. In addition to its pediatric researches the program will include teratology and genetics, physiology, biochemistry, and clinical research. It will stress basic research and research training, and the development of diagnostic and treatment techniques.

Areas of study will include malformations resulting from altered environment during the developmental period and genetic abnormalities, inborn metabolic errors, and various studies of the effects of drugs and infection on the fetus and mother.

Total cost of project: $3,011,210.
Federal Share: $1,724,000.
Date of Award: July, 1965.
Estimated completion date: July, 1967.

Walter E. Fernald State School, Waltham, Massachusetts

This Center is located on the grounds of an institution for the retarded and will place heavy emphasis on the retarded person as the object of study. Interchange with investigators in other fields will be encouraged, and research will focus on prevention and amelioration. Among the disciplines included in this research program are neurology, psychiatry, pediatrics, epidemiology, experimental psychology, cytogenetics and education. An unusual feature of this project is the close cooperation between the Fernald School, Massachusetts General Hospital, and the Harvard Medical School.

Total cost of project: $1,790,000.
Federal Share: $827,000.
Date of Award: May, 1965.
Estimated completion date: 1967.

George Peabody College for Teachers, Nashville, Tennessee

This College has a long and productive history of research and training in the field of mental retardation but in a circumscribed area of the behavioral sciences. The new Center will make possible the expansion of interdisciplinary research efforts and research training for a wider range of behavioral scientists.

In the newly created Division of Human Development, the program will primarily be directed at the educational, psychological and sociological aspects of mental retardation with strong emphasis on cultural deprivation. The uniqueness of this research program lies in its relatively narrow but powerful thrust on these vital dimensions of the problem.

Total cost of project: $3,543,547.
Federal Share: $2,496,000.
Date of Award: May, 1965.
Estimated completion date: 1968.

University of California, Los Angeles, California

The main focus of the research program in this Center will involve a combined biological and behavioral approach to the problem of mental retardation. It envisions cooperative studies among the Departments of Psychiatry, Neurology, Pediatrics, Biochemistry and other Divisions within the Medical School, as well as the Departments of Sociology and Psychiatry. Collaborative studies of a basic and clinical nature related to mental retardation will be undertaken.

The University has also received approval for the construction of a clinical facility for training and demonstration under Part B, Title I of the P.L. 88–164. These activities will be closely coordinated with those of the research center.

Total cost of project: $2,588,970.
Federal Share: $1,660,000.
Date of Award: January, 1966.
Estimated completion date: 1969.

Children's Hospital Medical Center, Boston, Massachusetts

This Center is closely affiliated with the Harvard Medical School and proposes an interdisciplinary research program directed toward the understanding, prevention and amelioration of the handicapped and the mentally retarded. The research team will include representation from experimental neurological sciences, behavioral sciences, genetics, metabolism and clinical research. Three additional senior scientists will be appointed to the Staff to man posts in genetics and metab-

olism, the neurosciences, and the behavioral sciences. This action is the largest single commitment in the Institution's history to research in a given field.

Total cost of project: $4,140,337.
Federal Share: $2,470,000.
Date of Award: January, 1966.
Estimated completion date: 1970.

University of Kansas, Lawrence, Kansas

The University of Kansas has a unique plan for the location of three research and research training units—at the Kansas Medical Center, the main campus of the University at Lawrence, and the Parsons State Hospital and Training Center, an institution for the retarded.

The long-range multidisciplinary research program is broadly conceived and focuses on biomedical and behavioral research relevant to mental retardation. Each of the three settings will emphasize a specific area of research. Studies at the Medical Center will include reproductive physiology, biochemistry, neurophysiology and fetal and neonatal pathophysiology. Studies on learning, language, and social behavior will also be conducted. At the Lawrence campus, research will feature residential and preschool studies of behavior, and the processes of socialization, communication, and learning. The program at Parsons will stress research in training of children with deficits in language, socialization and adaptive behavior, in academic attainment and vocational skills.

Total cost of project: $2,921,978.
Federal Share: $2,150,000.
Date of Award: September, 1965.
Estimated completion date: 1969.

University of Colorado, Denver, Colorado

Strong research programs in neurophysiology, neuropharmacology, behavioral sciences, developmental pediatrics, cytogenetics, nutrition, developmental and lipid biochemistry, and neurochemistry form the basic science research core of the Colorado center.

The Wheatridge State Home and Training School, the Colorado mental retardation training facility, and State and community health resources will provide additional resources for research through a coordinated program. Special studies in family and community health will be possible through these extra resources. Epidemiological and population genetic studies will be conducted among the special populations resident in Colorado and the Southwest.

Total cost of project: $442,647.
Federal Share: $331,985.
Date of Award: December, 1966.
Estimated completion date: 1968.

University of North Carolina, Chapel Hill, North Carolina

The University of North Carolina Child Development and Mental Retardation Research Center plans a broad program of research involving medical, psychological, educational and social sciences.

Two separate but administratively unified facilities will be constructed. The medical research facility will house a comprehensive research program including research in the clinical and basic sciences of medicine and health related disciplines.

The psycho-educational facility will consist of a unique arrangement of educational and care facilities with supporting research laboratories. The central research theme will be long-term, longitudinal studies of retarded children and children at risk of becoming retarded. Beginning in infancy or early age and continuing through the elementary school years of the children will be provided with a carefully engineered program and environment designed to enhance their intellectual, social and emotional development. Medical research here will include studies of the impact of optimal health care and the consequences of infectious diseases on development.

Total cost of project: $3,423,241.
Federal Share: $2,439,400.
Date of Award: September, 1966.
Estimated completion date: 1970.

University of Chicago, Chicago, Illinois

An award for movable research equipment was made to the University of Chicago to assist in equipping their Joseph P. Kennedy, Jr. Mental Retardation Research Center located in Wyler Children's Hospital. The research center is

contiguous with the Chicago Lying-in-Hospital which provides a resource for studies of prematurity and obstetrical conditions leading to retarded development.

Research in the center will focus on cytogenetics and population genetics, enzyme development, neurological and hematological investigations, biochemistry, virology, respiratory physiology, and developmental studies.

Moveable research equipment award only.

Amount of award: $66,375.

Date of award: September, 1966.

Activation date: 1966.

RESEARCH CENTER AWARD MADE AFTER JANUARY 1, 1967

University of Wisconsin Center

The grant program planned at the University of Wisconsin Center is comprehensive and broadly focused. A Bio-medical sciences unit will provide for research in neuro-physiology, neuro-metabolism and nutrition, and neuro-endocrinology and reproduction. The programs in the behavioral sciences unit range from those concerned with the effects of experience or social environment on human development to those directed toward the specific behavioral processes and definits in the retarded. The Central Wisconsin Colony, designed as a research and training facility as well as a residential unit for care and treatment, will work in close coordination with the University of Wisconsin Center.

Total cost: $3,017,335.

Federal share: $2,263,000.

Date of award: January 26, 1967.

Estimated completion date: January 1971.

Appropriations and approved applications for mental retardation research centers, Jan. 1, 1967

Fiscal year	Appropriation	Applications approved	Federal share
1964	$6,000,000	0	0
1965	8,000,000	4	$12,108,000
1966	6,000,000	3	56,854,000
1967	6,000,000	4	4,987,000
Total	26,000,000	11	22,949,760

Institutions	Total cost	Federal share	Estimated completion date
University of Washington, Seattle, Wash	$8,290,970	$5,700,000	1969.
Albert Einstein College of Medicine, Yeshiva University, New York, N.Y.	5,124,815	3,085,000	1968.
Children's Hospital, Cincinnati, Ohio	3,011,210	1,724,000	July 1967.
Walter E. Fernald State School, Waltham, Mass	1,790,000	827,000	1967.
George Peabody College for Teachers, Nashville, Tenn	3,543,547	2,496,000	1968.
University of California, Los Angeles, Calif	2,588,970	1,660,000	1969.
Children's Hospital Medical Center, Boston, Mass	4,140,337	2,470,000	1970.
University of Kansas, Lawrence, Kans	2,921,978	2,150,000	1969.
University of Colorado, Denver, Colo	442,647	331,985	1968.
University of North Carolina, Chapel Hill, N.C	3,423,241	2,439,400	1970.
University of Chicago, Chicago, Ill	[1]	66,375	1966.
Total	35,277,715	22,949,760	

[1] Movable research equipment award.

UNIVERSITY-AFFILIATED FACILITIES FOR THE MENTALLY RETARDED

Since its inception in 1963, fourteen Federal grants totaling $30,348,901 have been awarded under the program of Federal assistance for the construction of university-affiliated facilities for the mentally retarded. This program, authorized under P.L. 88–164, "The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963," was established to provide clinical facilities to assist in training physicians and other specialized personnel in the

field of mental retardation, or in demonstrating new techniques of specialized services for the mentally retarded.* As nearly as practicable, a full range of inpatient and out-patient services for the mentally retarded must be provided in facilities constructed with such grants.

The project grants to university-affiliated facilities represent a step forward in providing professional and technical manpower essential to the care, education, training, rehabilitation, and diagnostic services required by the mentally retarded. Following are summary descriptions of the types of facilities and programs which have been supported with these funds.

This construction program is administered by the Division of Mental Retardation, Public Health Service, Department of Health, Education, and Welfare.

Children's Rehabilitation Institute (John F. Kennedy Institute), Reisterstown, Maryland

One of the first applications to be approved under the program was submitted by the Children's Rehabilitation Institute, Reisterstown, Maryland. A grant of $2,360,250 was awarded, which will aid in the construction of a $3 million facility to be known as the John F. Kennedy Institute. This new clinical facility, to be located at the Johns Hopkins University, will train medical students, interns, residents, post-doctoral fellows, psychologists, hospital and public health nurses, social workers, and other specialists in the care of the mentally retarded.

The center will occupy 90,000 square feet of space specifically designed for the conduct of treatment, training, and research. In addition to a 60-bed inpatient unit, a full range of diagnostic and therapeutic services for outpatients will be provided.

Total cost: $3,147,000.
Federal share: $2,360,250.
Date of award: February 4, 1965.
Estimated completion date: June 1967.

Georgetown University, Washington, D.C.

Georgetown University has been awarded a grant of $1,500,000 to aid in constructing a new four-story addition to the Gorman Diagnostic Building on the Georgetown University campus. The new facility will allow for the expansion of the existing mental retardation clinic at the University. The new program will provide complete diagnostic and evaluation services, parent and child counseling, improved professional training programs, and a base for clinical and statistical research in mental retardation. The Georgetown Center will provide a valuable clinical resource to the retarded children of the Washington metropolitan area.

Total cost: $2,000,000.
Federal share: $1,500,000.
Date of award: February 5, 1965.
Estimated completion date: January, 1968.

University of Colorado, Denver, Colorado

A Federal grant in the amount of $369,000 has been awarded to the University of Colorado to assist in the construction of a new mental retardation center. The three-story building will provide some 6,400 square feet for medical personnel, clinical psychologists, social workers, nurses, nutritionists, dental hygienists, audiologists, and speech therapists working with the mentally retarded. The project is designed to coordinate existing services and to provide both a regional evaluation and consultation center and a continuing care plan for retarded children from nearby counties. The facility will serve as a regional referral center for mentally retarded children with difficult diagnostic problems or those in need of special laboratory services.

Total cost: $602,884.
Federal share: $369,000.
Date of award: January 3, 1966.
Estimated completion date: January, 1968.

Walter E. Fernald State School, Waltham, Massachusetts

Established in 1847, this school is affiliated with Massachusetts General Hospital and associated with a number of educational facilities in the Boston area.

The Federal grant of $724,725 will aid in the construction of a Community Evaluation and Rehabilitation Center on the grounds of the present school. The new facilities will provide programs for carrying out diagnostic and evaluation

*See "Mental Retardation Report" for November 26, 1965 and August 22, 1966 for additional information regarding this construction program.

procedures and for training in most of the medical specialities, special education, psychology, social work, nursing, and other areas. The total construction cost will be approximately $2.6 million.

Total cost: $1,347,000.
Federal share: $724,725.
Date of award: April 10, 1965.
Estimated completion date: September, 1968.

University of California, Neuropsychiatric Institute, Los Angeles, California

A grant of $2,638,335 was awarded to the University of California, Neuropsychiatric Institute to assist in the addition of four more floors which will comprise a mental retardation unit. This unit will provide three 20-bed wards for young, severely retarded children, ambulatory retarded children, and older children with varying degrees of retardation. Diagnostic studies of both outpatients and inpatients will be conducted in the facility. Attention will be focused upon the differentiation of functional retardation associated with emotional disorders from true retardation.

Total cost: $3,517,780.
Federal share: $2,638,335.
Date of award: July 29, 1965.
Estimated completion date: October, 1969.

University of Alabama Medical Center, Birmingham and Tuscaloosa, Alabama

The University of Alabama is the second institution to receive a grant for the construction of two university-affiliated mental retardation centers. An award of $2,180,494 has been made to construct training facilities at the University of Alabama Medical Center, Birmingham, and on the main university campus at Tuscaloosa. The Medical School presently maintains a variety of services for the mentally retarded which will be expanded to include an increase in diagnostic capacity and capability and a program of treatment and professional training in the various disciplines. The satellite facility at Tuscaloosa will provide facilities for specialized training of Ph. D. level psychologists in clinical and experimental psychology with content emphasis on mental retardation which will then balance the overall training programs insuring truly collaborative, multidisciplinary training.

Total cost: $2,907,326.
Federal share: $2,180,494.
Date of award: November 24, 1965.
Estimated completion date: January, 1968.

Children's Hospital Medical Center, Boston, Massachusetts

The Children's Hospital Medical Center, Boston, was awarded a grant of $863,250 to assist in the construction of a Child Development Research and Evaluation Center. The grant will aid in the addition of two and one-half floors to a new eleven-story outpatient department building which is part of the Medical Center complex, located within the Harvard Medical School area.

In 1929, the Children's Hospital created one of the first inpatient units in the country in which retarded children could be studied and evaluated by a team composed of pediatricians, neurologists, psychologists, and social workers with consultation available in other appropriate specialties including orthopedic surgery, psychiatry, and neurosurgery. The new facility will permit the hospital to expand its services. Patients will be referred to the new center by other clinics and divisions of the hospital and by physicians and community agencies. Not only the immediate Boston area, but much of New England, will share in the use of the additional services and training resources provided by the new clinical facility.

Total cost: $1,276,500.
Federal share: $863,250.
Date of award: July 6, 1965.
Estimated completion date: June, 1967.

Indiana University Medical Center, Indianapolis and Bloomington, Indiana

The mental retardation facility to be constructed at the Indiana University will be operated in two separate physical units: one to be located within the James Whitcomb Riley Hospital Child Development Center, Indianapolis, and the other—the Indiana University Developmental Training Center—to be located on the campus in Bloomington.

The center at the James Whitcomb Riley Hospital has served as a referral center for all difficult cases in pediatric diagnosis and treatment, and at least

40 percent of these patients are diagnosed as mentally retarded. This center has concentrated a major portion of its activities in the development of programs in all aspects of mental retardation. The new unit will serve primarily as a diagnostic and outpatient treatment center and as a training resource in the field of pediatrics. It will provide consultation services to physicians throughout the State and will screen admissions to the residential center at Bloomington.

The Bloomington center will house 40 children in eight "home units" under the supervision of cottage "parents." Training of specialists in behavioral sciences, speech and hearing, special education, and other areas will be conducted at Bloomington.

A Federal grant of $3,157,231 has been awarded to assist the two Indiana University projects.

Total cost: $4,277,635.
Federal share: $3,157,231.
Date of award: December 9, 1965.
Estimated completion date: April, 1968.

University of Tennessee, Memphis, Tennessee

The University of Tennessee has been awarded a grant of $3,199,710 to aid in the construction of a Child Development Center as a part of the University of Tennessee Medical Center which serves Western Tennessee, Eastern Arkansas, Northern Mississippi and the Southeastern tip of Missouri. Although a Child Development Center was established in December, 1956, this grant will provide the applicant with an opportunity to plan additional training programs for the disciplines in such a way as to bring about an interdisciplinary effort and will emphasize the contribution that each discipline will make in the amelioration of the problem for the mentally retarded. The Center will serve as a referral center to meet the increased demands for services to the mentally retarded in the service area. Close liaison will be maintained in developing Special Education classes in public schools for the educable and trainable and the development of a day care program for the severely retarded. A pre-school program for the mildly and moderately retarded and the development of sheltered workshops and the development of special classes for children with visual perceptual motor handicaps is planned.

Total cost: $4,266,280.
Federal share: $3,199,710.
Date of award: March 30, 1966.
Estimated completion date: November, 1969.

University of North Carolina, Chapel Hill, North Carolina

University of North Carolina will receive a Federal grant of $500,811 for the construction of a University-Affiliated Facility for the Mentally Retarded which will be known as the Child Development Center. The Center will have as its primary function the training of professional and specialized personnel in the diagnosis, treatment and management of retarded children. Other major responsibilities include the development of working relationships with practicing physicians and State supported clinics with problem patients who will be accepted and returned to the community after a comprehensive work up at the Center. The Child Development Center will have two related units: (1) the outpatient facility for intensive evaluation and (2) a day care facility for the retarded children. The outpatient facility will be staffed by a multidisciplinary team which will evaluate deviations from normal development and the establishment of treatment programs for the retardate and their problems. Longitudinal follow up will be a part of the clinic operations. The day care center will also be utilized as part of the treatment program and will likewise involve a wide variety of the necessary disciplines needed for the care, education and training of the mentally retarded.

Total cost: $667,748.
Federal share: $500,811.
Date of award: November 17, 1966.
Estimated completion date: November, 1969.

New York Medical College, New York, New York

The New York Medical College has been awarded a Federal grant of $3 million for assistance in constructing a center for mental retardation as an integral part of the Medical Center complex. The Medical College has operated a retardation center since 1950 and has an ongoing multidisciplinary approach to service, training, and research in the field. The expanded facility will allow an additional 500

patients annually to be accepted for evaluation and service. A 28-bed inpatient wing will provide intensive diagnostic, treatment, and training resources. Training programs will be conducted in pediatrics, neurology, psychiatry, and ophthalmology as well as in nursing, rehabilitation, and behavioral sciences.

The professional staff at the New York Medical College has gained national recognition in the field of mental retardation, and this Federal support will allow the applicant to enlarge the spectrum of training in mental retardation for all disciplines. All levels of retardation, from profound to mild with associated handicaps, will be represented in the clinical population, and provision is made for re-evaluation and follow-up therapy. Additional numbers of professional and specialized personnel interested in the field of mental retardation will be accommodated within the proposed facility.

Total cost: $4,000,000.
Federal share: $3,000,000.
Date of award: December 10, 1965.
Estimated completion date: May, 1969.

Georgia Department of Public Health, Atlanta and Athens, Georgia

The Georgia Department of Public Health has been awarded a grant for the construction of a University-Affiliated Mental Retardation Center known as the Georgia Retardation Center located in Atlanta and a satellite facility of the Center to be built at the University of Georgia campus in Athens. The Atlanta facility will house a high calibre treatment program that provides the basis for the clinical training of a complete range of professional personnel to work in community and institutional programs for the retarded. The Athens facility will provide space for an indepth evaluation of outpatients with emphasis being placed on training in special education, the habilitative services, and speech and hearing. In addition, professional training will be conducted in the other disciplines needed for the diagnosis and treatment, education, training and care of the mentally retarded.

Total cost: $4,125,550.
Federal share: $3,094,163.
Date of award: August 25, 1966.
Estimated completion date: November, 1970.

University of Oregon, Portland and Eugene, Oregon

University of Oregon and the University of Oregon Medical School has been awarded a grant totalling $3,706,500 with which they propose to construct a university facility for the mentally retarded consisting of two facilities, one in Portland on the Medical School campus and one in Eugene. Both units will become the components of an ongoing professional training and demonstration program for the mentally retarded. The proposed interrelationships between the two centers and the intercampus plan is based on the successful experience in a similar program in speech pathology and on ongoing pilot project in mental retardation which is presently being carried on at both campuses. The School of Social Work and the Department of Special Education at Portland State College will also participate in the training program to meet the training needs for the mentally retarded of the State. The proposed center will make it possible to coordinate and expand present clinical services presently being provided into one coordinated exemplary program directed towards the diagnosis and treatment of the mentally retarded. The Center will have as its objectives the further development of ongoing training programs; the expansion of the mental retardation laboratory clinic; the development and enrichment of curriculum development; the provision of an adequate number of specialized personnel needed within the communities of the State for the mentally retarded; and the introduction of the multidiscipline team concept for exemplary patient care; and the training of graduate and post-graduate students in the biomedical and behavioral sciences; development of short term courses in institutes for practitioners in medicine, dentistry and the allied health professions.

Total cost: $5,072,000.
Federal share: $3,706,500.
Date of award: July 27, 1966.
Estimated completion date: June, 1970.

University of Miami, Miami, Florida

The grant awarded to the University of Miami for the construction of a facility for the mentally retarded will be located on the campus of the School of Medicine and within the immediate vicinity of the Jackson Memorial Hospital and the National Children's Cardiac Hospital which are teaching hospitals for the Medical

School. The proposed program will provide clinical services for the mentally retarded and will serve as a focus for model of training practices and management of the mentally retarded. The promotion, expansion and initiation of training for research and biomedical, behavioral, educational, and social areas will be some of the objectives of the training programs. The programs will be devoted to seeking the causes and means of prevention as well as the methods of ameliorating the effects of mental retardation. The facility is expected to provide an opportunity to make training in mental retardation a part of the learning experience of all medical, nursing, and of undergraduates and graduate students in psychology, social work, special education, speech, and law. It is proposed that in addition to providing specialized services for the diagnosis and treatment, education, training and care of the mentally retarded that this facility will be a training site for professional personnel which will be interrelated on a multidisciplinary basis with the biomedical, social and behavioral aspects of mental retardation. Patient services will be on a multidisciplinary integrated approach to all clinical activity and comprehensive diagnosis will be a multidisciplinary function.

Total cost: $4,872,575.
Federal share: $3,054,432.
Date of award: November 16, 1966.
Estimated completion date: October, 1969.

Appropriations and approved applications, university-affiliated facilities for the mentally retarded, Dec. 31, 1966

Fiscal year	Appropriation (in millions)	Applications approved	Federal share
1964	$5.0	0	0
1965	7.5	4	$7,223,310
1966	10.0	6	12,769,685
1967	10.0	4	10,355,906
Total	32.5	14	30,345,901

Institutions	Total cost	Federal share	Estimated completion date
Children's Rehabilitation Institute, Reisterstown, Md	$3,147,000	$2,360,250	June 1967.
Georgetown University, Washington, D.C	2,000,000	1,500,000	January 1968.
University of Colorado, Denver, Colo	672,884	369,000	Do.
Walter E. Fernald State School, Waltham, Mass	1,347,000	724,735	September 1968.
University of California, Neuropsychiatric Institute, Los Angeles, Calif.	3,517,780	2,638,335	October 1969.
University of Alabama Medical Center, Birmingham and Tuscaloosa, Ala.	2,907,326	2,180,494	January 1968.
Children's Hospital Medical Center, Boston, Mass	1,276,500	863,250	June 1967.
Indiana University Medical Center, Indianapolis and Bloomington, Ind.	4,277,635	3,157,231	April 1968.
University of Tennessee, Memphis, Tenn	4,266,280	3,199,710	November 1969.
University of North Carolina, Chapel Hill, N.C	667,748	500,811	Do.
New York Medical College, New York, N.Y	4,000,000	3,000,000	May 1969.
Georgia Department of Public Health, Atlanta and Athens, Ga.	4,125,550	3,094,163	November 1970.
University of Oregon, Portland and Eugene, Oreg	5,072,000	3,706,500	June 1970.
University of Miami, Miami, Fla	4,872,575	3,054,432	October 1969.
Total	42,080,278	30,345,901	

Mr. ROGERS. I would like to see this list, and when you submit it to the committee may I have a list myself stating where it is located, how it would operate, what are the functions that it will carry out, and what are the major functions that will be carried out here of those who are already approved?

Dr. STEWART. Mr. Rogers, the functions will be, first, a specialized diagnostic facility for particularly tough diagnostic problems and other particular problems and then development of prime treatment plans. Second, is a training center for the variety of personnel that would

be needed in taking care of mentally retarded or in making diagnoses in the mental retardation field. Thirdly, it will provide a setting for the kind of research which is related to better diagnosis and better treatment. These are the three main parts, the service, the training, and the research areas.

Mr. ROGERS. How are these referred there to the university-affiliated facilities? Suppose I have a retarded child that I want to get into one of those. What do I do?

Dr. STEWART. Well, I would assume it would be from your physician who is taking care of your retarded child. He would refer the person and would get in touch with the university which operates in that area, a referral center—and the physicians within a broad area usually know of these.

Mr. ROGERS. You can come in to have consultations and so forth?

Dr. STEWART. Correct.

Mr. ROGERS. How many children will this take care of in this first grant that you are making in Maryland? What is proposed there?

Dr. JASLOW. We do not have the specific figure at hand for the individual, but we do have general figures averaging throughout the——

Mr. ROGERS. I said this one project I was concerned with. What is going to happen there?

Dr. LEE. We can get that for the committee. We will be glad to submit that with the list of projects and some illustrations of other university projects, because we do have some additional information on those.

(The information requested appears on p. 33.)

Mr. ROGERS. I would like to have something given to us to give us an idea of what is going to be accomplished, how many people will be taken care of, how many people will be trained in the projects that you have approved.

(The information requested follows:)

TABLE IV.—*University-affiliated facilities program estimates for each year of operation*

	Professional training	Basic training	New patients served	Patients served
Children's Rehabilitation Institute	178	231	120	493
Georgetown University	44	104	109	438
University of Colorado	48	735	105	475
Walter E. Fernald State School	98	364	160	625
University of California Neuropsychiatric Institute	222	443	150	720
University of Alabama	108	380	150	625
Children's Hospital Medical Center	73	263	170	569
Indiana University	103	748	158	610
University of Tennessee	103	289	124	600
University of North Carolina	34	314	75	600
New York Medical College	95	491	132	600
Georgia Department of Public Health	46	949	120	350
University of Oregon	241	903	203	1,051
University of Miami	279	258	125	475

Dr. STEWART. About 10,000 will be trained.

Mr. ROGERS. Out of 14?

Dr. STEWART. Out of 14, yes.

Mr. ROGERS. What period of time does this require to train?

Dr. STEWART. This varies because the training programs range from 3 year doctoral training programs all the way down to short-range lessons, for example, a year of training for people who need to learn a new skill.

Mr. ROGERS. Who administers this program, how is this program administered, this mental retardation program that we have approved in this law?

Dr. STEWART. The Division of Mental Retardation, Public Health Service, administers this program.

Mr. ROGERS. Is it connected at all with the National Institutes of Mental Health?

Dr. STEWART. No.

Mr. ROGERS. This is entirely different?

Dr. STEWART. Yes. We recently moved the retardation programs that were in the Institute of Mental Health and formed this new division consolidating the programs into a Division of Retardation.

Mr. ROGERS. Which were the three that you did?

Dr. STEWART. The mental retardation portions of the hospital improvement grant program in the National Institutes of Health, were transferred to the Division of Mental Retardation and combined with the effort we had in State planning. The mental retardation construction programs that we have placed in this new Division came from the old Bureau of State Services.

Mr. ROGERS. This was put in what? Combination of the old Bureau of State Services?

Dr. STEWART. The construction, the technical assistance, everything has been put together into one division with the exception of the university research centers which we are not asking for extension.

Mr. ROGERS. Under what bureau?

Dr. STEWART. Bureau of Health Services.

Mr. ROGERS. Of Health Services?

Dr. STEWART. That is correct.

Mr. ROGERS. But your mental health program is still administered through NIH?

Dr. STEWART. Through the National Institute of Mental Health which is a bureau.

Mr. ROGERS. Separate bureau?

Dr. STEWART. Yes.

Mr. ROGERS. While I am on that I might just like to ask this: I have heard some rumor which I hope has no foundation that there was some consideration of taking the National Institutes of Health out of the Public Health Service.

Dr. LEE. Well, since last fall consideration has been given to that idea and to the creation of a department of health.

Mr. ROGERS. Well, if it is a department it is different.

Dr. LEE. It would only be if it was a department of health and would stay within the health framework under any circumstances.

Mr. ROGERS. As I understand it the only consideration that would be given was if there was a department of health?

Dr. LEE. That has been our approach.

Mr. ROGERS. I would agree with that then. I would just hope that it would not be allowed out of the Public Health Service if the department were not formed. Would that be the present thinking?

Dr. LEE. That is consistent with our thinking; yes, sir.

Mr. ROGERS. Fine. Thank you. When will the community construction begin?

Dr. STEWART. There have been about 100 grants funded. There are two that have been completed.

Mr. ROGERS. Two?

Dr. STEWART. Yes.

Mr. ROGERS. Where are they located.

Dr. JASLOW. I understand one is near completion but I am no tsure where that one is.

Mr. ROGERS. I would like somebody to know where some of these things are because the committee cannot just take these out of the air you know.

Dr. JASLOW. The other is located in Chesterland, Ohio.

Mr. ROGERS. How large is that?

Dr. JASLOW. That is an extension that takes care of 114 patients which extended the original population of 66 by 48 additional.

Mr. BROWN. Excuse me, where in Ohio?

Dr. JASLOW. Chesterland, Ohio.

Mr. BROWN. Chesterland?

Dr. JASLOW. Yes.

Mr. ROGERS. That was a facility that took care of 66 or did you say 48?

Dr. JASLOW. Sixty-six, sir.

Mr. ROGERS. It has been expanded?

Dr. JASLOW. An additional 48.

Mr. ROGERS. What services do they offer there?

Dr. JASLOW. This is primarily a daytime activity of educational training and a sheltered workshop.

Mr. ROGERS. Are there any funds from any other agencies going in besides what we have put in from this program?

Dr. JASLOW. Operating funds? Construction funds came from both State and Federal sources and operating funds came from private, community, and State sources.

Mr. ROGERS. State? No Federal funds for operations?

Dr. JASLOW. Not in operations.

Mr. ROGERS. Do you anticipate that this would have to be funded for staff?

Dr. LEE. In that particular facility, Mr. Rogers? I believe if the present level of operations was maintained that Federal funds would not be provided, but if they expanded services in terms on scope or quality then I think it is possible that Federal funds might come in to expand the range of services.

Mr. ROGERS. I think it might be well for you to let us have for the record the areas that are constructed or when they will go into operation, how many people they will serve, what staff situation there is, if they are expecting to call on us for staffing or what. What about research? How much money is being spent on research in the mental retardation field?

(The information requested follows:)

GRANTS FOR THE COST OF PROSESSIONAL AND TECHNICAL PERSONNEL OF COMMUNITY MENTAL RETARDATION FACILITIES

ESTIMATED STAFFING NEEDS

It is estimated that community facilities authorized under the mental retardation facilities construction program for the three year period 1968–70 will provide

space to house services for approximately 51,000 retarded not now being served. Using a staff/patient ratio of 1/5, it is estimated that approximately 10,200 professional and technical staff will be required to initiate services for these retarded persons at an estimated total cost of $75 million. In addition, we estimate new services will be initiated in existing facilities for approximately 17,000 retarded. Initial staffing will require 3,400 professional and technical personnel at a total cost of $25 million.

(Questions regarding research are answered in Tables No. 1 and 2, pp. 12–15.)

Dr. STEWART. We have most of the research money of course in the National Institution of Child Health and Human Development and the National Institute of Neurological Diseases and Blindness.

It may not be defined or identified as research in mental retardation, it may be identified as research in oxygen lack during birth processes or something like this, but I do have those figures here. In the National Institute of Neurological Diseases and Blindness for mental retardation, the 1967 estimate totals $23,861,000.

Mr. ROGERS. This is for blindness?

Dr. STEWART. No. It is for research in mental retardation. The Institute of Neurological——

Mr. ROGERS. Research specifically for mental retardation?

Dr. STEWART. Not exactly. It is centered around the problem of mental retardation. The problem of cerebral palsy, brain damage during birth on the perinatal period, all are involved in this complex area. We do not know the specifics of it yet, particularly as they concern mental retardation.

Mr. ROGERS. Who is doing most of the research?

Dr. STEWART. Most of this is under training and research grants, but we do have a large intramural program on the perinatal problems at the NIH in Bethesda and in Puerto Rico where we are doing a lot of work with our free-ranging primates on which we do a great deal of our study of the problems of the oxygenation of the brain of the fetus and the newborn.

Mr. ROGERS. So this is prenatal work?

Dr. STEWART. It is perinatal; that is, surrounding the period of birth, and there is a great effort going on there. For the National Institute of Child Health and Human Development, the 1967 estimate is 12,078,000. Now that goes beyond what you might label purely mental retardation; it gets into learning problems, behavioral disorders, etc. Work purely in mental retardation would be $7.788 million.

Mr. ROGERS. That is doing research mainly? Is that under intramural or extramural?

Dr. STEWART. That is largely extramural research. We do have a small intramural program in the Child Health Institute in conjunction with the Navy at the Bethesda Naval Hospital. We are just developing our program.

Mr. ROGERS. Now, just now beginning? How many people would be involved therein in the beginning in the intramural approximately?

Dr. STEWART. I would have to get that for you.

Mr. BROWN. Excuse me for just a minute, but is the 7.788 part of the 12,078 or is it separate?

Dr. STEWART. No. It is part of the 12. Of the 12 million 7,788 can be identified exclusively in mental retardation.

(The information referred to follows:)

TABLE V.—*National Institute of Child Health and Human Development—Mental retardation research program, 1967 budget estimates*

[Dollar amounts in thousands]

	Estimated, 1967					
	Primarily mental retardation		Relevant mental retardation		Total	
	Positions	Amount	Positions	Amount	Positions	Amount
Grants:						
Research		$6,679		$4,290		$10,969
Clinical research centers		(198)		(0)		(198)
Fellowships		309				309
Training		800				800
Direct operations:						
Laboratory and clinical research [1]	32			0	32	
Collective research and development [2]	2			0	2	
Biometry Ep., and field studies [2]	3			0	3	
Review and approval [3]	9			0	9	
Program direction	2			0	2	
Positions, direct operation	48			0	48	
Total, mental retardation		7,788		4,290		12,078

[1] Includes positions related to the operation of the Diagnostic and Study Unit, and the Biomedical and Behavioral Laboratories at the National Naval Medical Center.
[2] Includes positions related to research contracts for mental retardation.
[3] Includes positions for support of extramural staff and training offices.

Mr. ROGERS. Any other funding for research?

Dr. STEWART. No. I think those are the two major sources for mental retardation.

Dr. LEE. I think Dr. Stewart made a very good point. For example, the amount of money that was spent on the development of a measles vaccine would not be found in the budget related to mental retardation. But this is a very important means of preventing mental retardation in youngsters who might have gotten severe measles and become retarded. So, it is hard to be as accurate as we would like to be on those things that might eventually affect this problem in terms of research.

Mr. ROGERS. I could say here——

Dr. STEWART. We do not know the etiology of so much mental retardation. There may be all kinds of research that is related to mental retardation someday, but we cannot determine these exactly at the present time. These are what we can identify.

Mr. ROGERS. How much are we presently aiming at at the present time. I realize there will be side benefits from other research you are doing, but it looks like 30 million at the present time. I would like to have a breakdown of who is doing this research now and have you got any encouraging reports of any progress being made of any specific nature? I have not heard of any lately.

(The information requested follows:)

RESEARCH PROGRAMS FOR MENTAL RETARDATION OF THE NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS

The National Institute of Neurological Diseases and Blindness (NINDB) has a variety of research projects diercted at the many facets of the neurological disorders of infancy and childhood. Many of these projects deal with mental retardation where it appears as a symptom, complication, or sequela of a disorder

of the central nervous system, and so this Institute is deeply involved with the problem of mental retardation.

Training programs of the NINDB

The training programs of the NINDB are directed toward the development of clinical neurologists and competent research scientists in the fields associated with the diseases of the nervous system. These are all basic tools required for any serious attack on the problem of mental retardation. The NINDB training programs are not responsible for providing service-oriented scientists. Training programs in Speech Pathology and Audiology are fundamental to therapy in the mentally retarded and receive strong support from the Institute.

Particularly important are the Institute programs for the training of pediatric neurologists, the discipline which is very often required to make the initial diagnosis of mental retardation. It is the pediatric neurologists who are leading the clinical fight against mental retardation. These programs for Pediatry Neurology Training are now progressing rapidly. There are eleven programs funded in 1967.

In addition, 5 Neurology Training Grant programs have been judged to have facilities and staff available to provide pediatric neurology training, and have done so, as follows:

University of Michigan Medical School, Ann Arbor.
State University of Iowa Medical School, Iowa City.
Yale University School of Medicine, New Haven.
University of Colorado Medical School, Denver.
University of Oklahoma School of Medicine, Oklahoma City.

Since 1957, 116 physicians have completed training in pediatric neurology (3 years); 55 are in training currently. Five persons have received advanced research training in various aspects of neonatal physiology as they relate to the central nervous system.

Based on a survey of those who had completed pediatric neurology training through 1963, it appears that about 90% are in academic positions, spending more than half of their time in research and teaching. Eight are directors of training programs.

Intramural research programs of the NINDB

Four separate sections of the NINDB intramural program are conducting research relevant to mental retardation. These are the Collaborative Project, the Laboratory of Perinatal Physiology, the Laboratory of Neurochemistry, and the Section on Child Neurology.

Number of scientists (M.D., Ph.D.)

Collaborative projects (plus 172 supportive personnel)	25
Perinatal physiology (plus 64 supportive personnel)	10
Neurochemistry	5
Child neurology	2

Extramural research programs of the NINDB

Major extramural expenditures are associated with the Collaborative Project for Perinatal Research but the Institute also provides support for other projects which may lend information relevant to mental retardation. These include studies of inborn errors of metabolism, congenital defects, birth injury, hyperbilirubinemia, and learning and behavior.

NINDB expenditures relating to mental retardation

The FY 1967 expenditures of the NINDB in the area of mental retardation totaling $23.8 million can be separated as follows:

[In thousands]

	1967
Training (including fellowships and traineeships)	$9, 500
Intramural	4, 461
Extramural Grants	9, 900
Total	23, 861

NINDB supported research programs relating to mental retardation

Scientists have long suspected that neurological and sensory disorders of childhood, including cerebral palsy, mental retardation, deafness, and epilepsy are associated with prenatal, natal, and postnatal damage to the nervous system.

For this reason, the Collaborative Perinatal Research Project—a joint endeavor of 14 medical centers and the National Institute of Neurological Diseases and Blindness—was begun in 1959. This study was designed to determine the relationships between factors affecting women during pregnancy and the neurological and sensory disorders which may develop in their offspring.

The Institute is also supporting through extramural grants many other individual projects related to these areas which will yield important insight into the normal development and functioning of the central nervous system as well as the factors leading to mental retardation during gestation, infancy and childhood.

1. PRENATAL STUDIES

Epidemiological and genetic studies are being carried out in an attempt to establish possible patterns of inheritance or other causative factors leading to neurological disease and mental retardation. These include inborn errors, chromosomal abnormalities, and congenital malformations.

Inherited diseases are among the leading causes of mental retardation and represent the "inborn errors of metabolism". These may be abnormalities of carbohydrate, protein, or lipid metabolism. The Institute has initiated a program of study of these diseases in order to understand their basic nature as well as their role in the resulting mental retardation.

Chromosomal abnormalities and congenital malformations continue to receive Institute-supported attention. Efforts are directed at establishing the causes of these abnormalities and, hopefully, developing methods of prevention. The possible role of such physical agents as drugs and poisions is also receiving direct attention.

Intrauterine infections are important factors leading to severe destruction of the brain and major mental impairments. Special interest is directed at the role of viruses including Rubella (German Measles) and Cytomegalic Inclusion Disease and at the role of the fungus, *Toxoplasma gondii*, in producing neurological damage. Particularly important are efforts to produce a vaccine for Rubella (German Measles) which may cause congenital abnormalities in the offspring when the mother is infected during the first trimester of pregnancy. At the Laboratory of Perinatal Physiology in Puerto Rico, studies of pregnant monkeys are being carried out to see if this disease has the same effect in primates, and if so, whether this laboratory model can be used for a variety of tests.

2. PERINATAL FACTORS

Regarding inborn metabolic errors, many states are now requiring tests in infancy for phenylketonuria, an example of this kind of disease. Many children will be examined in infancy and followed through childhood in order to relate early diagnosis to the effectiveness of therapy. Through research of this kind, it is hoped to discover how early these diseases do appear and when to begin treatment. There are more than 200 known metabolic abnormalities of which no more than 6 may be amenable to present therapeutic approaches. Continued study is necessary to enlarge these treatment programs. The biochemistry of these diseases and the relationship of these biochemical activities to brain function are being studied. This may elucidate their role in the development of mental retardation.

3. POSTNATAL STUDIES

The examination of the brain injured child is becoming more important. From a wide variety of causes, many children have minor degrees of brain injury which can markedly affect their development. Studies are under way linking the pathological patterns of brain damage to functional development. Again the Collaborative Study will be increasingly valuable in providing both normative data and incidence statistics relative to mental retardation.

Mental retardation is a potential sequela of meningitis or meningo-encephalities. Institute programs are investigating the mechanisms involved as well as proper preventive and therapeutic approaches.

The early diagnosis of mental retardation is at times fraught with difficulties. The Institute continues to support programs for the refinement of diagnostic techniques. The problem of minimal brain dysfunction is undergoing re-evaluation to assess the current status of and to apply advanced techniques to this difficult area.

Mental retardation is often a sequela of hydrocephalus and brain tumors in childhood. The development of appropriate surgical or pharmacological therapy remains an objective of the Institute.

Progress through research supported by the NINDB

Major contributions to our fund of knowledge in basic and clinical areas have resulted from NINDB supported research.

Collaborative perinatal project

In 1966 the Project passed a significant milestone with the birth of the last baby to the more than 60,000 mothers registered by the 14 collaborating institutions. This event, which marked the end of the obstetrical phase of the Project, signalled the beginning of a period of intensive analysis of study results collected so far.

Although final analysis of all study data will not begin until 1974 when the information-collection phase of the project is completed, important preliminary findings have been made available. Some of these findings were reported in the second scientific session of the Project held in 1966. These are outlined below.

I. Assess significance of known or suspected factors

1. The impact of the nationwide rubella (German measles) epidemic, which produced 20,000 to 30,000 neurologically impaired babies, and the role of toxoplasmosis and cytomegalic inclusion body virus (salivary gland virus) have been further clarified. Of particular importance, deafness secondary to congenital rubella covers a spectrum from partial to complete. Recognition of this fact is of utmost importance.

2. Congenital toxoplasmosis is more common than phenylketonuria, with an incidence of one in 2,000 births. National Institutes of Health scientists tested serum specimens from 23,000 pregnant women for antibodies to Toxoplasma. They found that 47 women had high titers or showed significant increases in antibody during pregnancy. The babies of these 47 women were investigated in detail. Five infants with growth abnormalities definitely had congenital toxoplasmosis. In ten other cases, the disease was suspected. Six of these had motor retardation, two were stillborn, and two died in the neonatal period. Efforts are now being directed toward determining the mode of transmission of toxoplasmosis, and means for its prevention and treatment. The recognition of the role of toxoplasmosis in the etiology of mental retardation is most significant in that the elimination of known causes of mental retardation can effectively reduce the total number of cases.

3. Among the leading causes of prematurity are placenta previa, premature placental separation, and incompetent cervix. There is no known prevention for the first two conditions, but surgical treatment of the incompetent cervix, a relatively recent obstetrical development, appeared to reduce fetal loss, increase neonatal survival rate, and reduce neurological abnormality.

4. 19% of neonatal deaths were associated with evidence of intrauterine infection.

5. Prematurity appears to be the greatest single factor associated with birth defects. Whatever its cause, prematurity has a close relationship to neurologic damage. Only 7 to 10 percent of infants are classified as premature—either by a weight of less than 2,500 grams or by time of gestation. But these premature births account for 70 percent of neonatal deaths. Premature babies have three times as many abnormalities as normals.

6. Maternal health is of paramount importance. A study of the association of maternal age and parity to pregnancy outcome reach a number of interesting conclusions. The best time for a woman to have a baby is between ages 20 and 27. The most successful pregnancies are the second and third. The most unfavorable pregnancy results are in very young (teenagers) and elderly mothers. The study also showed an unfavorable outcome in women having too many pregnancies too soon, at 22 years of age or less. Early and frequent pregnancies were associated with an increase in neonatal mortality, prematurity, low mental scores, neurologic abnormalities, and anemia. Mothers' prior pregnancy records served as good indices for prediction of future pregnancy results.

A new and promising area of investigation is the possibility of predicting birth weight early in pregnancy. This may provide a basis for changing the natural course of certain pregnancies. The birth weight of the infant appears to be the best gauge for predicting neonatal mortality and infant morbidity.

Project researchers used 37 variables to analyze data on some 6,500 women. More than two dozen of the 37 variables provided statistically significant simple correlations with birth weight. Smoking appeared to be a particularly important factor. Women who smoke a pack of cigarettes a day, for example, could expect to have a baby about 165 to 180 grams lighter than a baby born to the average

non-smokers. A history of hypertensive disease was also associated with a drop in birth weight.

Glomerulonephritis was associated with low birth weight, diabetes mellitus with prematurity, maternal convulsions during pregnancy with a three-fold increase in mortality and morbidity. Vaginal bleeding appeared the most ominous obstetric sign relative to outcome, and the maternal death rate seems to have reached a low-point below which there is likely to be no advance. Mothers' with severe heart disease did not have increased numbers of babies with serious neurological disorders.

7. In a pilot survey of several hundred babies in the Collaborative Project, nearly two percent were found to have evidence of Rh blood incompatibility. It is current therapy in participating hospitals to employ exchange blood transfusions if Rh incompatibility results in high bilirubin levels, treatening infant jaundice and kernicterus (involvement of the brain). Permanent brain damage from kernicterus can often be prevented or reduced by a method of exchange transfusion developed in 1947 by Drs. F. H. Allen and L. K. Diamond of Harvard Medical School, now NINDB grantees. The widely-used method makes use of the umbilical cord for exchange transfusion, in contrast to an original method introduced in 1944 where a leg artery and arm vein were used for blood exchange. Under NINDB grants, further studies by the investigators have resulted in improvements and refinements in the technique. These include the use of albumin, a serum protein which binds bilirubin and facilitates the removal of greater amounts of bilirubin than otherwise.

8. Caesarean section under local anesthetic gave favorable results. Since general anesthetics may depress the infant's respiratory centers, local anesthetics may be preferable. A careful assessment of these data is necessary.

II. Early recognition of the subnormal or partially subnormal child

1. A clear definition of high risk mothers can be made. This information can be very useful for such agencies as the Children's Bureau which are interested in this problem.

2. The newborn examination at delivery and in the neonatal period is vital. Prolonged labor in itself was not deleterious unless associated with complications such as uterine dysfunction or mechanical dystocia. Analyses of 17,000 records of the Institute's Perinatal Project have demonstrated the value of the 1-minute and 5-minute Apgar scores in predicting an infant's chances of surviving the first critical weeks of life.

3. Methodology for the recognition of deviation from normal childhood development has resulted from the Collaborative Project and such methodology can be readily adapted to early detection programs.

III. Critical evaluation of therapeutic procedures

1. Evidence has accumulated in recent years that certain changes in the blood caused by oxygen deprivation could be minimized and damage lessened through the use of intravenous injections of glucose and alkali. Additional research studies confirm the value of this treatment, which could have important implications in preventing certain forms of cerebral palsy and mental retardation.

2. Early surgical intervention in hydrocephalus has proved of importance in reducing the mental impairment which results in the absence of surgery. In addition, it is now recognized that certain individuals, previously described as mental retardates, actually suffer from a milder form of hydrocephalus (low pressure). Surgery may save the affected individual from an otherwise dismal future.

IV. In-depth studies of disease and disease processes

1. Respiratory distress syndrome remains an enigma. Recent studies with oxygen, glucose, and bicarbonate are promising, however, oxygen toxicity has been detected in the lungs after prolonged exposure to high concentrations.

2. A simple and rapid blood test for diagnosing German measles (rubella) has been developed. It provides identification of antibodies to rubella infection within 24 hours compared with about 2 weeks necessary for earlier methods.

Institute virologists participated in work which for the first time characterized the virus of German measles (rubella). (1962) They demonstrated that women of child-bearing age are a high-risk group for rubella infection, a cause of cerebral palsy and other maladies in the fetus, (1963) and helped lay the groundwork for future development of a rubella vaccine through trials of an experimental vaccine in human volunteers. (1963) They also pointed out inadequacies in gamma globulin prophylaxis revealed by rubella antibody tests. (1963)

Laboratory of perinatal physiology

This laboratory provides the experimental complement to the clinical investigations of the Collaborative Project to test in primates those questions raised by this study. Investigators have been able to produce cerebral palsy and mental retardation. This allows them to simulate or reproduce conditions occurring during pregnancy and delivery which may be causal factors. In addition, modes of therapy and methods of prevention can be evaluated.

Intrauterine transfusion is being investigated in collaboration with a New York scientist. This treatment has yielded impressive results in prolonging fetal life in cases of Rh incompatability and thus has promise in combatting erythroblastosis fetalis.

Inborn errors of metabolism

Certain diseases associated with defective or absent proteins can be accompanied by mental retardation unless preventive measures are instituted. Research is making it increasingly possible to identify the conditions associated with such defects, thus paving the way for prevention of organic mental impairments.

This past year, the identification of enzyme deficiencies in Gaucher's disease and in Niemann-Pick's disease (both associated with mental impariment), was made by a neurochemist of the National Institute of Neurological Diseases and Blindness. In a 1966 summary of medical progress on inborn errors of lipid metabolism he traced the chemical search leading to the finding of the cause of these two disorders.

The defect in Fabry's disease, marked by the accumulation of a related complex lipid, was also elucidated by this investigator. Although mental retardation is not a significant factor in this disease process, the mapping of these related biochemical pathways is *a truly important advance.*

The investigator presents potential modes of treatment, dependent on the outcome of future research. These include the regular administration of the enzyme to the patient, the donation of a healthy spleen to replace a spleen which cannot produce the necessary enzyme, or the possible administration of an appropriate DNA or RNA to correct the error in the pattern of heredity of these children.

The NINDB neurochemist also suggested that the identification of an enzyme involved in an inborn error may allow the detection of parents who are normal themselves, but carry both a normal gene and a defective gene for an inborn error of metabolism. Tissue culture techniques may elucidate the heterozygous state (having both normal and defective genes) in the parents.

Institute grantees and a European investigator discovered the defect in another inborn error called metachromatic leukodystrophy (MLD). Lack of effective amounts of an enzyme, called a sulfatase, allows certain complex lipids to accumulate with attendant motor and mental retardation.

These grantees also found a significant sulfatase abnormality in each of two patients with gargoylism (Hurler's syndrome).

Another scientist supported in part by a Neurology Institute grant found three previously undescribed ketones in the urine of a patient with the form of mental retardation resulting from hyperglycinemia. Further research seeks an explanation for the presence of these unusual chemicals.

An NIH biochemist (NIAMD) has recently described the enzymatic abnormality in Lesch-Nyhan syndrome, an inborn error of metabolism accompanied by mental retardation and self-mutilation. The over-production of uric acid in this syndrome presents an interesting comparison with gout, an adult disease associated with disturbed uric acid metabolism.

An institute grantee developed the test for detection of phenylketonuria (PKU) which is now being employed in screening programs throughout the country. This effort has promoted the institution of screening tests for other diseases associated with mental retardation. The NINDB supports many of these pilot projects.

Neonatal jaundice

Efforts are continuing to find still more effective ways of counteracting this harmful impact of bilirubin in the newborn. Drs. Blanc, Johnson, and Silverman have demonstrated that the administration of gantrisin, a commonly used antibiotic, sensitizes the body to the harmful effects of bilirubin by impairing the binding of bilirubin by albumin.

Important to these investigation have been studies of kernicterus in animals. Artificial production of kernicterus in rats has been carried out by Dr. J. F. Lucy at the University of Vermont, in monkeys by Dr. J. B. Rauck, Jr., University of

Washington in Seattle, and Dr. W. F. Windle and others at the NINDB Perinatal Physiology Laboratory in Puerto Rico.

Dr. R. Carhart, Northwestern University, recently described a probable mechanism of hearing loss in kernicterus. Application of this data may help explain the role of kernicterus in cerebral palsy and mental retardation.

Retrolental fibroplasia

Retrolental fibroplasia (RLF), which caused blindness in thousands of prematures over a ten-year period, has been largely eliminated by limiting the administration of oxygen to clinical emergencies, and by restricting the concentration and period of administration of exygen when it is required. This disorder, which affects the retina and vitreous of the eye and was one of the most common blinding disorders, has been virtually erased as a result of studies by NINDB grantees and others.

The recent advances in the treatment of the respiratory distress syndrome of the newborn involve the use of high oxygen concentrations. Many of the young scientists involved in these investigations may not be able to appreciate the magnitude of the RLF problem in 1940–50. To forestall a recurrence of this problem, the NINDB is sponsoring a joint conference of pediatricians and ophthalmologists. This conference will allow the establishment of guidelines for proper surveillance of RLF.

National Institute of Child Health and Human Development

RESEARCH PROGRESS IN MENTAL RETARDATION

Chromosomal abnormalities

Chromosomes are the structures in the nucleus of the cell which carry the genes. Gross abnormalities of chromosomes are one cause of spontaneous abortions and birth defects, including mental retardation, in humans. An estimated 1 our of every 150–200 live births results in a chromosomal abnormality. The cause of these abnormalities are generally unknown and some of their effects are lethal.

Researchers supported by the National Institute of Child Health and Human Development at the University of Colorado are examining evidence that human sex chromosomes defects may not occur by chance, but are due to specific environmental factors.

Beginning in 1963, these scientists have surveyed 7,000 newborns in Denver, Colorado. They found that babies with abnormal numbers of sex chromosomes tended to appear in seasonal clusters (during a five-month spring and summer period).

In the first two years of the survey, they found an incidence of sex chromosome aberrations of 0.6 percent during one five-month period. No aberrations occurred in similar populations either before or after this period. There was also an elevated incidence of Down's syndrome (mongolism) during this same five-month period.

During the past two years, they found another cluster of sex chromosome aberrations in a five-month period with a seasonal distribution similar to that in the first cluster. These findings suggest that X chromosomes (sex chromosomes) and autosome No. 21 (the chromosome involved in mongolism) may be equally susceptible to production of abnormalities due to some external factors, though the particular environmental factors involved are still to be identified. The Colorado researchers are currently looking into the possibility that a atent virus infection in the mother around the time of conception may be one factor involved.

Another National Institute of Child Health and Human Development grantee at the Michael Reese Hospital and Medical Center, Chicago, Illinois, found clusters of chromosomal abnormalities about the same time as those found by the Denver group.

Congenital defects appearing in the two clusters, totaling 11 births, were of the type caused by autosome defects. Further study by the Chicago group showed a number of deaths occurred among babies conceived at the same time as those with chromosomal defects.

Since German measles (rubella) and infectious hepatitis in particular are suspected of causing chromosome aberrations, these grantees studied the occurrence of infectious diseases in Chicago during the times abnormal babies were conceived. However, only a significant increase in common measles (rubeola) was found during the first cluster. Studies to date fail to support the role of rubeola as a cause of chromosome changes noted in these newborns. This group is con-

tinuing its studies of chromosome aberrations and extending them to investigate stillbirth and spontaneous abortion populations.

Dermatoglyphics and diagnosis of pre-birth damage

Dermatoglyphics (finger, palm and sole prints) have been seen to be abnormal in a number of clinical disorders including certain chromosome defects.

A National Institute of Child Health and Human Development-supported researcher at the University of Minnesota in Minneapolis has been conducting dermatoglyphic studies in three types of mental retardation not associated with obvious chromosomal errors. The three types were: phenylketonurics, representing a genetically determined type; rubella-damaged individuals, representing an environmentally induced type; and idiopathic retardates, whose mental retardation may have resulted from genetic or environmental factors, or both.

The Minneapolis study showed that the phenylketonurics and idiopathic retardates differed very little in dermatoglyphic characteristics from a group of mentally normal controls.

The rubella-damaged group did exhibit abnormal dermatoglyphic patterns, including increased frequency of transitional and simian palmar flexion creases, of whorl patterns on the finger tips, and a tendency toward more palmar patterns than normal.

In this project, although differences noted were significant, their magnitude was not sufficient to allow them to serve as an effective diagnostic aid. However, the implication of the results are that an environmental agent, like rubella virus, may damage the fetus early in gestation and cause changes in finger, palm and sole prints that could be easily detected at birth. Thus, dermatoglyphics may prove a useful tool for identifying damage occurring during the intrauterine period that is not associated with chromosomal errors.

Cultural and environmental retardation

Severe retardation is often caused by metabolic errors or chromosomal defects. However, the effects of cultural and environmental conditions can cause mild retardation which accounts for a high proportion of all retardation in America. Since this type of retardation contributes to the self-perpetuating nature of disadvantaged groups in society, ways to combat it must be found.

National Institute of Child Health and Human Development-supported educators and psychologists from the University of Kansas are attempitng to find the best ways to educate and train the deprived urban child and his family. One approach they are using is to study the parent-child interactions in preschool training.

They have found that when the preschool child is given a choice between playing with dolls, blocks, etc. and taking a "lesson," given by the mothers themselves, the children will select at least one lesson a day. Indeed, some children are selecting to repeat the same lesson at least five times a day.

In order to investigate the potential of this approach to education, the Kansas group begun a parent-child interaction program in 1965. At first teachers worked with mothers at home; then this was expanded to a cooperative nursery progam to provide greater training opportunities for the mothers in the project. Finally the mothers, after appropriate instruction, began trying to teach their own children many of the skills necessary for later achievement upon entering school.

The mothers in this study used 106 special lesson "kits" prepared by the Kansas City investigators. They were taught to give the children special attention, smiles, praise and other signs of approval to reinforce a child's progress during a lesson. These methods were encouraged in place of progress gained through threats, nagging and the like. When the mother was teaching her own child, although the incidence of praise increased, she could not stop nagging her own offspring. This year, the mothers are teaching children other than their own and the incidence of nagging has almost literally disappeared. Now, the children choose the mother to teach the lesson they select and appear to enjoy learning more.

The Kansas City researchers are confident that parent-child teaching and training, such as that demonstrated in their program, may be one answer to breaking the self-perpetuating cycle of cultural "deprivation." They feel that the application of the findings in this study will not only help remedy current learning deficits of these children but prevent further deficits from occurring through the improved mother-child interactions.

Cultural and environmental conditions which contribute to school failure and functional mental retardation can be combatted through incentive techniques in remedial instruction programs. Educators have often noted the difficulty in motivating children from culturally deprived families. The same University of

Kansas investigators running the parent-child interaction program have set up a program to investigate motivations for academic achievement.

In this study, children who attend remedial instruction courses, after regular school or work, are given classroom tasks within their realm of ability. They are given a variety of incentives for achievement. Also, they must show gradual improvement over the year to continue receiving incentive awards.

The students are given incentive points for doing homework and for grades earned in regular school classes. These points can then be traded in for such things as daily snacks, fields trips, picnics, toys, or clothing when enough are accumulated. During the first year of this program, the pupils from a sixth grade remedial classroom showed significant academic progress with the grade average for the entire group being raised from D to C.

Public school achievement test scores for this same group showed they had gained 1½ years during the year compared to only a 6-month gain in the two years prior to remedial class attendance. A group from the same area, not enrolled in this program, showed only 0.8 years gained on the achievement test and only 0.2 of a grade point gain in school marks.

Utilizing a similar incentive program, these same researchers ran a remedial classroom for junior high school drop-outs who were members of the local Neighborhood Youth Corps.

These students were motivated to achieve by being paid for each problem worked correctly in class.

Pre- and post-achievement tests in this group showed an average gain of 1.3 years in only two months of instruction compared to an average 0.2 year's gain for Neighborhood Youth Corps children working at regular jobs and not attending classes.

Sensory and motor disorders and learning

Mental retardation is associated with impairment of an individual's adaptive behavior. Impaired adaptive behavior may be reflected in maturation, learning and/or social adjustment. Learning problems, in particular, range from difficulties in the acquisition of simple skills, such as self feeding, to more complex symbolic and abstract learning problems encountered during the school years.

Since learning depends greatly on sensory and motor input, these systems must be sound to assure an effective learning experience.

In school, many children are slow learners because of poor performance secondary to various sensory and motor deficits. For example, children with cerebral palsy, having poor motor coordination, may not do well in school, and some of the mental retardation associated with cerebral palsy may actually be impaired learning ability due to poor motor coordination. While completely deaf, blind or mute children have their handicaps recognized and, hopefully, compensated for in the school environment, those with partial or subtle impairments of sight, hearing and speech are not always recognized. Often their learning difficulties are simply attributed to limited intellectual ability or to a lack of effort. With better diagnostic and remedial instruction techniques, these children can be saved a lot of misery and be helped to achieve their full intellectual potential.

National Institute of Child Health and Human Development grantees at the Albert Einstein College of Medicine, New York City, have developed a series of tests aimed at helping to recognize partial impairments affecting learning. These tests check the child's auditory-visual, visual-touch, and visual-motor activities and their ability to integrate these important sensory-motor activities.

The Einstein investigators' auditory-visual integration test involves the child listening to a series of taps, and then matching up what he hears with a series of dots on paper. Through this test, the Einstein group has shown that reading disabilities seem to reflect an interference with auditory-visual interaction. They have also found that even though retarded readers are poor at auditory visual integration, this is not the sole factor involved in their disability. They note that this type of sensory integration in its more complex and general form may be one process underlying adaptive behavior and thus IQ. They found that individuals who can perceive and integrate many sensations, such as touch, vision, and hearing, are very likely to be the more "intelligent" ones.

This continuing research is based on the principle that each sensory system in the body interacts with and is modified by other sensory systems and that even the simplest sensory functions are continuously modified by activity in the other senses. The Einstein researchers believe that, in humans, integration of sensory systems is a developmental process which follows a definite age and growth curve.

Only through continued support of research in many disciplines, and through multiple approaches focusing on the multiple factors involved can we find adequate

methods of preventing, alleviating and ameliorating the problem of mental retardation.

Dr. STEWART. I think in the area of the perinatal period, the area I was talking about, we have had some very interesting results on this.

Mr. ROGERS. What specifically? Could you give us an example or two?

Dr. STEWART. Well, the development of the intrauterine transfusion, the effects of anoxia on the fetus, the question of whether the anoxia is what is causing the problem or whether it is mechanical problems in the birth canal. There has been a great deal of effort devoted to this and we think we understand more about the perinatal causes of brain damage which may result in mental retardation than we did, say, 5 years ago. We have a long way to go yet.

I think that the hopes look very good for the development of a German measles (rubella) vaccine which will also, if it works, prevent German measles in pregnant females. This program could also prevent much mental retardation in the future.

Mr. ROGERS. What is the projection for this? Do we know about how soon we might anticipate something like that?

Dr. STEWART. At the present time we expect that a German measles vaccine is 2 or 3 years off.

Mr. ROGERS. It is that far off? Are sufficient funds being devoted to this?

Dr. STEWART. Yes, there are. The problems are technical problems. You can grow the virus in a small quantity in the laboratory but when you talk about manufacturing a vaccine for the entire country you have to grow it in large quantities. This is one of the technical problems. And the stability of the virus is a problem.

Mr. ROGERS. If you had additional funds to devote to this culture, virus, would this speed it up?

Dr. STEWART. No, I do not think so. The funds we have in the present budget are sufficient. These are technical problems that just have to be solved. The Congress did add extra funds to our budget last year to pursue this program and at the present level——

Mr. ROGERS. It is not a matter of funds at all for this work?

Dr. STEWART. That is correct.

Dr. LEE. There is another area in which significant advances have been made in understanding the problem of mental retardation. This is particularly important for the developing country. It is the understanding of the relationship between protein malnutrition and mental retardation and the need to meet the protein requirements of infants. Not only infants of course, since their needs are usually met by nursing mothers, but also following that period. Here again, the Institute of Child Health and Human Development has supported some of the fundamental research that has been done in this area which may be of real significance in preventing mental retardation.

Mr. ROGERS. Is not there a test given now to children to try to determine this and a mental retardation condition that can be corrected by diet?

Dr. STEWART. Yes; there is. Phenylketonuria is the disease and you can correct this situation before the mental retardation occurs.

I might add one other thing, Mr. Rogers. I think our understanding of family planning also is an advance in this area. We now have a pretty good idea that proper spacing of children, particularly in

mothers of high risk, where there is a possibility of having a premature child or some other defect which also raises the risk of having a mentally retarded child. The proper use of family planning in a medical setting is probably one of the better tools we have at the present time to do something about mental retardation.

Mr. Rogers. Let me ask you this: in this center, these community centers on vocational rehabilitation, what funding does the Federal Government do on this?

Dr. Lee. I will give you the estimates for 1967, for the programs supported by the Vocational Rehabilitation Administration. Grants to States, $23,104,000; research and demonstration projects, $3,005,000; training and traineeships, $1,870,000; special rehabilitation research and training centers, $750,000; innovation grants, $300,000; expansion grants, $200,000; and research and training (this is the special foreign currency program, Public Law 480), $408,000. The total from the Vocational Rehabilitation Administration for fiscal year 1967 is $29,637,000 and that is projected to increase in fiscal year 1968 to $37,633,000. The major share of the funds are in the grants to the States, increasing from $23,104,000 to $31,080,000. Those are for vocational rehabilitation services.

Mr. Rogers. Now, your community mental—community facilities for the retarded would also have a rehabilitation unit in it or a program?

Dr. Stewart. Yes, it may. Again we have this wide range. I do not recall whether you were here——

Mr. Rogers. Yes, I heard the five or six things here.

Dr. Stewart. One could have a rehabilitation unit in the center or it could be a sheltered workshop which is a partial rehabilitation unit.

Mr. Rogers. In the mental health program we required the five services to be present?

Dr. Stewart. That is correct.

Mr. Rogers. In order to get approval from the Mental Health Service. Now, you are not requiring that in the mental retardation. Why is this?

Dr. Stewart. The reason is that you have a much broader scope of types of services in mental retardation. In providing services to the mentally retarded you have almost every kind of human service that you and I need only these have to be specialized types of services. In the mental health field one can describe the score of services which are most likely to be used by the large bulk of the mentally ill people. Many mentally ill people will use the range of services of acute hospitalization, outpatient, inpatient, day are, and this sort of thing whereas in the mental retardation field you almost have to fit the range of services to every individual that comes in. The scope of the mentally retarded is so great, all the way from complete dependency to those who just need some specialized service to become fully active individuals.

Mr. Rogers. Is not that all the more reason to require all the services to be presented in a center?

Dr. Stewart. Again, you cannot put all these into a single center. The community has these. These are not only health services. There are a great deal of social services and residential services and day care and educational services. The educational services in many

communities are already being supplied in part or in full by the educational system. You try to fit it into the educational system as close as you can. The same with the social services, the day care, and these things. So the idea of putting all this in a center is less feasible than in the mental health area. Now, we do require in the applications for the construction of whatever facility the community intends to build and we will require it in the staffing grant applications of those who service this group that the group of services which we are being asked to make a grant for be connected with the services that are already available in the community. So we are coming in and filling in gaps or expanding existing services so that more of the mentally retarded can be served rather than the way we are doing it in the mental health field. The nature of the patient is different.

Mr. ROGERS. Well now, I know there are many areas where we do not have any services at all, but I thought this was one of the programs which we were first presented with, this program that the great need was to get some facilities because there was no place to send a child.

Dr. STEWART. There is no question about that. There are many communities where there are no places to send a child and what they will need to do——

Mr. ROGERS. The schools could not take care of them.

Dr. STEWART. That is correct. They were unable to fund any special education or special services under their school district.

The first or one of the first things that one has to have in a community is a diagnostic and evaluation system.

Mr. ROGERS. I would think this would almost be necessary everywhere, would it not, if you have services for the mentally retarded?

Dr. STEWART. That is a prime type of service.

Mr. ROGERS. Are you requiring that there be such a service everywhere one of these centers are located if it is not in the community?

Dr. STEWART. If we are being asked to construct a certain type of facility we would have this facility fit in with the rest of it.

Mr. ROGERS. Suppose there is no diagnostic center?

Dr. STEWART. They were, let us say, asking for a construction grant for a sheltered workshop, for example. I think that we would want to go back to that community and talk to them about it. Is it all right to have a sheltered workshop, but is it really your high priority of need?

Mr. ROGERS. Is this included in any State health plan that would be presented by the health authority?

Dr. STEWART. We had under another law, Public Law 88–156, which provided funds for several years to assist the States in planning their mental retardation programs in the State. This was I think 4 years in all and they have completed their plans. What kinds of facilities they need, what kinds of services they need to develop, where they need to be located, and what their priorities are.

Mr. ROGERS. You have seen these?

Dr. STEWART. Yes, sir.

Mr. ROGERS. I will conclude this in just a minute. I have taken much too much time. Suppose there is a rehabilitation center where they are serving the mentally retarded, can funds from this be used

in such a facility maybe to build it, to expand it, or to help staff it? I know we have one in West Palm Beach that is doing an excellent job.

Dr. LEE. To meet the needs of retarded specifically in terms of adding to a facility?

MR. ROGERS. Adding and staffing?

Dr. LEE. You can do both. State grants, can pay for adding to the facility or pay for the services if there is a facility that provides the services.

Mr. ROGERS. Where do they go?

Dr. LEE. They could construct this additional facility to serve the needs of the mentally retarded and if new legislation is passed funds would be available to help support the development of initial staffing.

Mr. ROGERS. Of the additional facility?

Dr. LEE. Correct.

Mr. ROGERS. It would not be of existing facilities, but it would have to be additional?

Dr. STEWART. The facility could receive a grant for staffing for initial operation of new facilities or for new services in existing facilities for the mentally retarded.

Mr. ROGERS. Now what use are you making of the foster grandparent program for the mentally retarded? Is this connected into your program at all or what?

Dr. JASLOW. Very closely. We have been watching this with interest and it is being used in many of the institutions for the retarded at the present time.

Mr. ROGERS. Are you encouraging this? Are you providing any funds?

Dr. STEWART. Yes. We have been working with the Administration on Aging in developing this into a meaningful program for older individuals who would like to do something which is both satisfying and constructive.

Mr. ROGERS. What point have you gotten to to really rock it as such?

Dr. JASLOW. Mainly consultation with our regional people in the field, making sure that agencies in the field are aware of this program as an additional resource for improving services.

Mr. ROGERS. Now, I hope that you will take a closer look at this program because it serves, as you say, Doctor, two purposes. It is an aid to the aged in giving them responsibility and perhaps additional income in doing these services. And from my experience in Florida it has been amazing for the retarded. In Fort Myers, Fla., at the center there we have used this program now, the foster grandparent program, and they say the results have been quite amazing. Young children who have begun 4 hours a day of attention of the grandparent, as such foster grandparent, from just no more than care and love, have responded to a degree that they did not anticipate. Many of them who could not even talk and were not saying anything are now talking just by some attention and care. So I would hope that as you expand your program for the mentally retarded you would try to bring in these programs and coordinate them closely with what experience has shown would be most helpful in this program.

Dr. JASLOW. We have some figures here, sir. The number of mentally retarded children served through this program in 1965 were 801 and it jumped in 1966 to 2,133. The reports we have been getting have been extremely satisfactory and encouraging.

Mr. ROGERS. What has been done to increase the 1967 program?

Dr. JASLOW. This program is not handled in our particular agency.

Mr. ROGERS. Well now, if it is going to help mentally retarded, why is it not?

The foster grandparent program is funded by the Office of Economic Opportunity and administered by the Administration for the Aging.

Dr. JASLOW. We have been continuing to make people aware of the program, as I say, and we hope to use this wherever possible.

Mr. ROGERS. Could you take another look and see about getting it in your program? That is what I am talking about, where they have used the program. It is probably a new innovation, but it had remarkable results from my understanding of it and if it does warrant that it ought to be tied in your program.

Dr. LEE. If we can serve more of the retarded certainly we will take a look and see how we can foster a more progressive development of this program.

Mr. ROGERS. I would like to have a memorandum on this; what can be done, what will be done, if it is necessary for congressional action, what action should be taken.

Thank you Mr. Chairman. I apologize for taking so long.

Mr. JARMAN. Mr. Brown?

Mr. BROWN. Thank you, Mr. Chairman. I am always fascinated by Mr. Rogers' questions because he touches on many things that I am also interested in. However, my questions are going to have to be a little more fundamental since I do not have the experience that he has on this committee. If I understand title 7 of the Public Health Service deals with prevention research, is that basically fair or correct in mental retardation?

Dr. STEWART. Yes, this section on the building of a research facility for mental retardation was for research per se.

Mr. BROWN. In effect, prevention research, cause of mental retardation?

Dr. STEWART. Research in the causes of mental retardation, improved ways to diagnosis, improved ways of treatment but more on the fundamental lines of causes of mental retardation.

Mr. BROWN. Eleven of these have been planned or were provided?

Dr. STEWART. When this legislation was before Congress the first time we talked about the need for about eight of these research centers devoted to the research of mental retardation. In fact, we have come out with 12.

Mr. BROWN. I see, the other way around. And are any of these in being now underway?

Dr. STEWART. One will be opening its doors in another month or so.

Mr. BROWN. That is the first one?

Dr. STEWART. That is correct.

Mr. BROWN. You are not submitting any requests for any additional facilities of this type?

Dr. STEWART. No. We think that the 12 mental retardation research centers that we are talking about are sufficient to accomplish what we

started out to achieve. Now, in addition, of course, there is a great deal of research going on in research facilities which is not labeled research in mental retardation. These research efforts will have a relationship to finding causes of mental retardation and these facilities will continue to be eligible for research facility grants. In addition we have added the word research to the extension of the university-affiliated clinical facilities program because there is a certain amount of research that can go on in that setting where we have individual patients. What we are after here is to improve diagnosis, and improve treatment and evaluation of methods which we use for other applied areas.

Mr. BROWN. I gather that part of the research that you are talking about is going to be in the $23,861,000 in the prenatal and perinatal studies.

Dr. STEWART. That is part of the research project I was referring to before.

Mr. BROWN. Is there a change in emphasis? Are you moving it into another area and abandoning the regional center area?

Dr. STEWART. Not at all. It is our feeling that the emphasis on research in mental retardation in these 12 centers in addition to the national research effort in many other university laboratories, is a sufficient resource of research facilities to carry out all the research that is necessary to be supported in the area of mental retardation.

Dr. LEE. Also it is important to see how in fact the multidiscipline centers work. This is a new approach to the problem of mental retardation in terms of bringing together people from a variety of special diciplines. Since we have not had any experience in the operation of these programs, we felt it was best to go ahead with these multidisciplinary centers. This was a recommendation of the President's Panel on Mental Retardation. It was agreed that 12 was about the right number to be established. So it was decided to stand back and take a look to see how well this approach works. Certainly in the future, if this proves to be a very productive research approach we would come back and ask for more funds for this kind of program.

Mr. BROWN. This one concerned me. I did not know whether you were making a value judgment before you got the first one on the line or not.

Dr. STEWART. No, sir. It seems to us that these 12 research centers, over the next couple of years will increase the research efforts in finding the causes of mental retardation. In addition all the other research facilities that are being supported will give us a good research effort into the future.

Now, if after they are opened it looks like there are difficulties in future development of research in this field, we will reassess the program.

Mr. BROWN. Under the Mental Retardation Facilities Construction Act, title 1, part B, as I understand, deals with research only in diagnosis, care, and training, is that correct, and does not deal with any research in etiology or cause?

Dr. STEWART. It is most likely to be the type of research that is related to diagnosis and treatment and evaluation of these systems. In the university-affiliated clinical facilities where you are in a sense acting as a special diagnostic and treatment center for the area, you have a problem referral center. We have a setting where we can carry

out research on these kinds of things, where we are training people and evaluating how well they do something. It seems only logical to put research services and training under these facilities.

Mr. BROWN. Are these two activities of the regional center and the university center all affiliated directly with medical schools only?

Dr. STEWART. Yes, they are. But, they do not have to be. The university-affiliated training center does not have to be only at the medical school; it can be at another appropriate part of the university.

Mr. BROWN. Are the regional centers affiliated directly with medical schools?

Dr. STEWART. For the most part, they are affiliated with medical schools.

Mr. BROWN. Back to that chart here and the question of mild, moderate, severe, and profound. I am trying to find a distinction in this definition of mild retardation, in my mind the kind of attention being given this rather significant portion of the 6 million people you are talking about. In Ohio we have in the public school system a separation into slow learning groups which is located generally within the school itself, that is the school building, or at least within the school system and administered directly by the school system. With reference to the retarded then the school system contributes to what is usually a separate and distinct individual facility for those that are defined under the law as retarded but it deals only with youngsters of school age. The statutory school age in Ohio is 6 to 21, I think.

Dr. STEWART. Yes.

Mr. BROWN. My question is, Whether or not I would find in the Ohio definition between slow learning and retarded all of these mildly retarded 89 percent that you have?

Dr. STEWART. I do not know what it would be. The range of IQ in this category of mild that we have on the chart is from 52 to 67, while the average IQ is 100. I do not know what the slow learner range would be in Ohio.

Dr. LEE. Certainly some of those children would be slow learners in the mild category. There may be other slow learners who may not be retarded.

Dr. STEWART. They may have learning defects, specific defects, not necessarily mental retardation. Some may have had communication troubles with development and, therefore, are slow learners. Their IQ may be all right, but they are having other difficulties which pay put them in the slow learning group.

Actually, Operation Headstart is an effort below the school age to provide a culturalization and learning process to try to teach some of those who may be in the mild retardation group on the IQ scale itself.

Dr. LEE. Dr. Weiner is here from the bureau of the handicapped in the Office of Education and might also wish to comment on this.

Dr. WEINER. I think I would refer this question to Dr. Heller who is a specialist in this area.

Dr. HELLER. Mr. Brown, in Ohio the slow learner would include the group that we are referring to in the chart as mildly retarded. The moderately retarded in Ohio are handled by the department of hygiene and would include the lower group, the trainable group. But they do not——

Mr. BROWN. Trainable group of mildly retarded, now?

Dr. HELLER. No, sir. The trainable group that we are referring to as moderately retarded, below 52 would be handled by the department of hygiene and what we commonly call the mild are handled as slow learners. This is the terminology for that child.

Dr. STEWART. It might be helpful to your, Mr. Brown, if I describe the definitions that are used in this chart. The profound have an IQ from zero to 19. These are so seriously handicapped they cannot survive unless they are constantly cared for, sheltered.

Mr. BROWN. If I may interrupt. No; go ahead and finish.

Dr. STEWART. The severe. They are severely handicapped and cannot adapt to the demands of community living unless they are sheltered in some way. Then the moderate; they are trainable for the most part and may require some protection or sheltered environment. And the mild; they are able to perform adequately and adjust in limited ways to the demands of society and can be positive workers in society. They may need assistance here and there or as they are developing; a slow learner, for example.

Mr. BROWN. Well, in the trainable moderate 6 percent are these people such that after they reach 21 they can care for themselves in terms of survival but not in terms of financial income or resources?

Dr. STEWART. This is correct. They usually can take care of themselves, their own personal daily living and can do some progressive endeavors in a protective environment like a sheltered workshop group where with a certain amount of protection they can produce goods or other things. But, as far as their own daily living, they can take care of themselves. They do not need an attendant.

Mr. BROWN. But a portion of the mild then, if properly trained and given a school, could perform useful work and maintain themselves independently and graduate so to speak into productive citizenship of some kind providing not too severe demands are made upon them?

Dr. STEWART. We think there is a fair portion or a very large portion who could achieve this state.

Mr. BROWN. Do you have any idea as to what that is?

Dr. STEWART. No, I do not. Would anyone like to venture a guess? But I think that you, in a sense, gave the definition of the mild group. Our purpose with respect to the mild group would be to accomplish just what you said: To be able to be a productive member of society as long as there is not too much strain on them.

Mr. BROWN. What I am concerned with is we have established or you have a program of determination of cause or an effort to determine cause and to prevent the incidence of retardation.

Now, the next question is how do we maintain these people and that apparently is covered in this legislation up to a certain age, but those who can be trained and rehabilitated, is there in this legislation the assistance that they might need for this kind of training? One of our programs again in Ohio is that the public schools come in and help up to age 21, but if they had not been adequately trained by then in most of the communities which have, well, what I would consider from what you said fairly progressive programs, they have cut off at 21, and maybe another year or two would help them come to this progressive status.

Dr. STEWART. The program in this legislation has no age limits, but it is not the help that you would want in this situation. The Vocational Rehabilitation Administration has programs which can now

reach down to an age which is I think 15 or 16 to a person who lacks a period of training of some 18 months and could become employable. And their program, the Federal-State program of vocational rehabilitation can pick up the individual who has gone as far as he can go in the educational system and move him into the job system and job market.

Mr. BROWN. They trained 14,000 or the State trained 14,000 in the Federal-State matching program?

Dr. STEWART. We think it will be 19,000 this year.

Mr. BROWN. They are trained on the job or individually, or can they be trained in the retarded school. Can the vocational rehabilitation program come into the established retarded school and provide either facilities, equipment, or supervision?

Dr. STEWART. They can provide the training in whatever setting is appropriate in the State. They in a sense purchase the training from training schools or crafts or any other type of effort that would fit this person's ability. I am talking about the mild group now. I am talking about the group that has gone so far in education and now at 15 or 16 can be fitted with a job.

What the vocational rehabilitation program does is try to work with the individual from the medical and from the rehabilitative standpoint of training to fit him with a job.

Mr. BROWN. So we could bring these things together in a retarded school.

Does this legislation provide for the purchase of an existing building or the rehabilitation of an existing building in addition to construction funds?

Dr. LEE. Renovation can be done. You cannot purchase, but you can renovate a facility or build a new facility.

Mr. BROWN. Should it not include the purchase of an existing building which might in the long run be cheaper than construction at this time?

Dr. LEE. Well, in the past it has been our feeling in going over the various ways in which the moneys could be spent that if there were existing facilities in the community, the community in the main could make them available. In using this approach we have attempted to meet the more urgent needs for facilities by constructing the specific kinds of facilities needed.

Mr. ROGERS. Would the gentleman yield?

Mr. BROWN. I yield.

Mr. ROGERS. I think we amended the mental health bill to allow acquisition which might be broadened to cover here.

Dr. STEWART. That is correct. We did amend the mental health bill for the purchase of buildings.

Mr. ROGERS. And it says in the definition also according to the report here, provide for facilities for the mentally retarded.

Dr. STEWART. I remember when it came up during the hearing last week. You are quite right.

Mr. ROGERS. We have not yet passed it, but when it is passed, it is not yet law.

Dr. STEWART. I remember when it came up at the hearing it covered both mental health and mental retardation.

Mr. ROGERS. It will help in this program that you are talking about, acquisition. I believe it is in the process of being done.

Mr. Brown. What about specialized equipment?

Dr. Stewart. Yes. They can purchase specialized equipment and this equipment is defined as having a lifetime of 5 years or more. It is not expendible equipment like paper and pencils and things like that.

Mr. Brown. Do you have any thought about the population size to be covered by the care centers?

Dr. Stewart. Again, Mr. Brown, I have to go back to what I was talking about with Mr. Rogers. You cannot visualize this as a center that has all the services in it for all of the mentally retarded in some geographic area. What we are providing grants for is the construction of a facility which the community feels and has shown to us they need as a part of, or in addition, to their services for the mentally retarded in this area. So that particular facility will be meeting the needs of that number of retarded who require the specific service in a facility. I cannot answer the question that you propose because I do not know what the total services needed would be.

Mr. Brown. In other words, there is really no standard that you all have in mind for a kind of facility?

Dr. Stewart. The standard would be a demonstration of need in the community. There are many communities that do not have anything and there are some which do not have a particular type of service and they have a demand for it.

Mr. Rogers. Going back to this State plan, have they not pretty much set forth the services in this State plan? Would it not be of help in determining this figure?

Dr. Stewart. Yes.

Dr. Lee. One care center might serve a neighborhood, the other a whole community.

Mr. Brown. I am still concerned about a program for retarded from one to six. Under Ohio's system we do not have any, or I am not aware of any, program which takes care of this problem. Then we get into the public school area where there is assistance and community action now because it is encouraged and assisted by the public school and takes the youngsters up to 18 or 21 and then whether he is finished or not dumped out of the system and the need may not be met. Now, you have reassured me on the upper end; what about the lower end?

Dr. Stewart. Your are quite right. There are such great needs One of the greater needs was the diagnosis and evaluation of preschool children. It has only been in the last decade or so, or even less than a decade, that we have had enough ability to deal with or feel competent or our diagnosis of mental retardation in the very young child, particularly those in the mild group. Now there are the seriously mentally retarded that can very frequently be diagnosed at an early age. But the real lack is the proper diagnosis and evaluation, evaluation meaning a plan for life in a sense, at the preschool age. It should be done as early in life as is possible, technically speaking.

Dr. Lee. Under the Childrens' Bureau program for crippled childrens' services, funds are available for grants to the States. These grants are administered in the State health department with few exceptions. Many States include the mentally retarded under their definition of crippled children. Initially it included children with orthopedic handicaps, then cardial, then the brain and neuro-

logical; and in many States, I am not sure of the exact number, it also includes mentally retarded youngsters under the definition of crippled children. So they are eligible for payment for services. This mechanism is also being used to develop services.

Mr. BROWN. I understand we have another witness and I do not want to pursue these questions further in detail but I would like to make a few comments.

It seems to me that you should proceed with a certain degree of caution with reference to the separation of a department of health because, particularly in the mental retardation field, you are dealing with an education matter and in States such as mine where the education and retardation programs are considered more akin than are retardation and health.

Dr. LEE. I should say, Mr. Brown, that we are not considering a separate department of health. It would be a sub-Cabinet department within HEW. We definitely do not think it should be developed separately because as I pointed out they are interrelated.

Mr. BROWN. I understand, but your comments mislead me. I thought you were thinking in terms of a separate department of health.

Dr. LEE. I am sorry that you misunderstood.

Mr. BROWN. And the other question I would ask is why—I think I know the answer but I still think it is a valid question—why are we separating mental health and retardation from the general health problem? It seems to me that we ought to be a little more mature than that approach which I think is old fashioned.

Dr. STEWART. I think the major reason is that there is such public apathy and lack of understanding in mental retardation that we need an extra emphasis which started with the President's Panel on Mental Retardation. Second, while many of the——

Mr. BROWN. One man's extra emphasis in another man's segregation. I am not sure that I agree with that kindly comment. I would not pursue the question and I see no reason for you to. It just struck me that complete separation is a little unnecessary and perhaps not too wise administratively.

Dr. LEE. Under the comprehensive health legislation, which terminated this year, Congress approved public health service grants-in-aid programs to the States. Mental retardation was included in that. It is now under the grant program for the development of comprehensive services. It is up to the State to decide how those funds will be used. This will help to coordinate more effectively at the State level, mental retardation programs with the total health programs in the State, setting up, as you know, the State health planning agency to better achieve this integration into the mainstream.

Mr. BROWN. I think they could just as effectively be done without the separation within the National Institutes of Health.

Mr. ROGERS. I think what you have tried to do probably is to target these problems that have been neglected for quite a while. And I think in mental retardation they have tried to forget them, and eventually it is anticipated, I presume, that they will be brought under the comprehensive planning program as you suggested, Mr. Brown.

Let me just ask a question or two. Of the funds for 2 years, as I recall we granted them available for 2 years?

Dr. STEWART. Yes, sir.

Mr. ROGERS. Have you used all of the funds. You have used them through 1967, is that right? They will not carryover in 1968?

Dr. STEWART. There will be a carryover in community construction grants.

Mr. ROGERS. Just a quick rundown. What I have heard from the Mental Health Service and the mentally retarded centers, it seems to me they are far ahead in the mental health, is this true?

Dr. STEWART. I think you are quite right.

Mr. ROGERS. Why is this? We passed the bill at the same time?

Dr. STEWART. First, I think that the effort in mental health at the State and local level had been greater, more data was available, more community organizations were available, and these types of things.

The mental retardation started I think from apathy and very little community organization, very little effort on it, and we have had to, in a sense, develop this whole effort. Now, I think it is rolling quite well. I would say that we were about a year behind or a little less then a year behind the mental health effort, but we have caught up, I think, this year with the mental health program.

Dr. LEE. I think it is commendable that it has gone as well as it has, because there was concern in the mental health field, the training problems, the research programs, as well as a number of interested people.

Mr. ROGERS. I think mental retardation was the stepchild and needed some emphasis, and I am glad to see some emphasis now.

Thank you very much for your testimony. It will be most helpful if you would furnish the committee with the information asked for.

Our next witness is a distinguished colleague from New York, Congressman James Scheuer. The committee will be pleased to receive your testimony.

STATEMENT OF HON. JAMES H. SCHEUER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. SCHEUER. I want to thank the chairman and the committee for letting me testify out of turn today. In deference to the lateness of the hour, I will be extremely brief.

The amendment I am proposing has been drafted by the Office of Education and is similar to about a dozen amendments that have already been accepted in school construction legislation; in the Elementary and Secondary Education Act, the Higher Education Act, and other school development bills. In the case of these programs under the jurisdiction of the Commissioner of Education, it is provided that in the design and construction of facilities, maximum attention be given to excellence of architecture and design and that in the case of model schools for the deaf, maximum attention be given to innovative auditory and visual assistance.

I hope the committee will consider sympathetically both of these more or less technical amendments. We have found out that it costs no more to build a school environment that is attractive and colorful than a bare-brick structure. It elates the kids, enhances their sense of well-being and gives them a radically different sense of society's measure of their own worth and, therefore, adds to their sense of self esteem and security, and propels them through the educational process. It might be appropriate to encourage building into the school such things as closed circuit television and any other innovative auditory

or visual devices that are appropriate for the special treatment of retarded children.

Mr. ROGERS. We will ask the Department to comment on this and let us have their thinking on it and I am sure the committee will go into this very thoroughly.

(See HEW report dated May 8, 1967, p. 7.)

Mr. ROGERS. Any questions? Mr. Brown.

Mr. BROWN. I have no questions other than perhaps to ask you to comment on the obvious thing which occurs to me and that is, how one equates excellence of architecture and design and some of the other things in this amendment, works of art and so forth versus taking care of 1 percent more retarded children?

Mr. SCHEUER. I think the cost-benefit implications of building a school that is colorful and gay with a stimulating atmosphere are that at whatever it costs to build a school it makes sense to take 1 percent and put it into the visual, stimulative effects to make the school a pleasant place for the child.

Most of the money we put into a school or an apartment house is in foundations, iron and steel, cement, plumbing, and electric wires. Although only a small percentage of it that shows, it is the part that shows that makes an impact on the person—whether it is an apartment house, school, or office building. We have had testimony, for example, on the Elementary and Secondary Education Act, from the former superintendent of construction in New York when this amendment was pending, and he said that where they had put this 1 percent into visual esthetics, the children felt that society had a stake in them and they felt pride in themselves and pride in this colorful, attractive place that society had built for them and the broken windows and scratched walls and general vandalism, which costs $6 or $7 million a year in New York City public schools, plummeted. I think you must find on the basis of savings on these operational and maintenance costs, that you have saved more than the 1 percent investment in visual amenities and esthetics.

As far as architecture and design is concerned, it costs no more at all, at whatever price level you want to build, whether it is a public house or Waldorf Towers. A good architect will build a more attractive building. The same goes for schools. I am not asking for a radical uplifting of the budgets of our schools. I say whatever your budget is, per square foot construction per budget, or cubic foot construction per budget, or per classroom construction per budget, good architecture makes a radical difference.

And what this bill does is simply give the Surgeon General a little bit of leverage in working with local communities to make sure they have done what they can do to get first-class architecture.

There are no absolutes. I do not believe that any Federal official should start vetoing local architecture in the community but it gives them a talking point.

But frankly we think the local community will be very receptive to some guidance and counseling and would very much like to have the direct vote as to architecture and design at 1 percent.

Mr. ROGERS. Thank you very much for your testimony. It was most helpful to the committee and we will consider your amendments.

The committee will adjourn until 10 o'clock tomorrow.

(Thereupon, at 12:05 p.m., the subcommittee adjourned to reconvene at 10 a.m., Wednesday, April 26, 1967.)

MENTAL RETARDATION FACILITIES

WEDNESDAY, APRIL 26, 1967

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON PUBLIC HEALTH AND WELFARE,
OF THE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met, pursuant to recess, in room 2322, Rayburn House Office Building, at 10 a.m., Hon. John Jarman (chairman of the subcommittee) presiding.

Mr. JARMAN. The subcommittee will please come to order.

As we continue the hearings on H.R. 6430, H.R. 7688, and H.R. 5110, our first witness this morning is Dr. Elizabeth Boggs, accompanied by Mr. Robert Gettings.

We are very pleased to have you with us.

STATEMENT OF DR. ELIZABETH BOGGS, REPRESENTING THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN; ACCOMPANIED BY ROBERT GETTINGS

Dr. BOGGS. It is a pleasure to be here, Mr. Chairman.

We are representing the National Association for Retarded Children, and we are very grateful for this opportunity to speak in support of legislation which has been of very essential importance in developing the aid for the retarded.

Our association is a nationwide voluntary association dedicated to the twin goals of preventing mental retardation and ameliorating its tragic effects. We speak for the "consumers of services" who, in the case of the mentally retarded, are usually unable to speak for themselves. Our concern extends to the mentally retarded of all ages and all degrees of disability.

Our members are found in every State of the Union. We are concerned not only with the school-age child, but the preschool child and the adult, as was brought out yesterday.

We have local organizations in most of the large communities and many of the smaller ones. We also have units in overseas outposts where there are members of the armed services. In this way we feel we are in very direct touch with the needs of the mentally retarded as they are felt at the community level.

Mental retardation affects the lives of millions of our citizens and causes annual economic losses totaling billions of dollars. Against this background the few million dollars of annual expenditure called for in the legislation before us seems almost inconsequential.

Nevertheless, we feel that these and other Federal expenditures can have an impact out of proportion to their size, if wisely spent.

The potential impact of Public Law 88–164, the Mental Retardation Facilities Construction Act of 1963, is already apparent. We are here today seeking your action to reinforce and enhance that potential.

We have here a chart which I would like to show you which indicates the distribution of the various types of grants that have already been approved under the several parts of the Mental Retardation Facilities Construction Act.

The square symbols indicate the location of the mental retardation research centers. The triangles show the distribution of university-affiliated facilities, and the other symbols indicate diagnostic and day and residential facilities funded under part C.

I think you will see that the impact is widespread, and if we were to underlay this map with a populatioin distribution, I think you would also see that on the whole the benefits are well distributed.

For the benefit of Mr. Satterfield, that little cluster that seems to be in the District of Columbia is partly in Virginia. There are two projects, one of them a multiple-purpose project, in the northern Virginia area.

That Federal aid is needed and could be well expended in vastly larger amounts than already contemplated, few will deny. However, we do not come today asking for money which cannot be found during this period of fiscal stringency now facing our Nation.

Rather, we ask of the Congress and the administration that what has been well begun be still more effectively continued, and that planful approaches be consistently supported, that the legitimate expectations of the State and community agencies be realized, that the highest priorities be attached to the greatest needs, and that artificial barriers to the most efficient utilization of funds be removed.

A well managed Federal attack on the problem of mental retardation must involve a variety of agencies within the Department of Health, Education, and Welfare as well as certain other departments.

Education, Rehabilitation, and Welfare must play their appropriate parts along with the Public Health Service. We seek to develop, over the shortest feasible period of years, adequate authority in each of these Federal operating agencies to cover formula and project grants in support of services, grants for continued planning, for research and demonstration, for professional training, and for construction as they apply to the mentally retarded. Today we deal with a portion of the responsibility of the Public Health Service.

With respect to the particular focus of the legislation we are discussing here, the President's Panel on Mental Retardation stressed the need to develop types of services not heretofore available. The emphasis on community-oriented programs has revolutionized society's thinking about mental retardation and has become a basic tenet of our modern philosophy of care and habilitation of the mentally retarded.

After examining the adequacy of community mental retardation facilities, the President's Panel, which reported in 1962, noted that "there is a shortage of physical facilities for many types of needed programs for the retarded, including classrooms, workshops, 'activities centers,' day care, half-way houses, and full-scale residential care."

In the area of day and residential facilities alone the Panel found a need for over 200,000 places in 1962. Current data indicates that this is a serious understatement of the need.

The Department of Health, Education, and Welfare, in response to the Panel's report, sponsored legislation in 1963 to assist in the construction of community facilities for the mentally retarded. The resulting program, authorized under part C of title I of Public Law 88–164, has induced State and local public and voluntary agencies to take the first tentative steps toward developing a network of community mental retardation facilities.

It is well to recall that, unlike the Community Mental Health Centers Construction Act, part C of Public Law 88–164 was originally proposed because both the Public Health Service and the President's Panel on Mental Retardation recognized that many of the most urgently needed facilities for day and residential care and habilitation of the retarded could not be funded through the authority granted to the hospital and medical facilities program or any other existing Federal construction authority. New legislative authority was required for this purpose.

During the 3 years this program has been in operation, and really it is less than 3 years because it was not funded until 1965, communities have provided tangible evidence of their willingness to respond to Federal leadership.

Indicative of this grassroots interest is the amount of non-Federal matching funds which have been raised for the 106 projects approved under this program as of March, 1967. For these projects public and nonprofit agencies at the State and local level have provided $58.4 million, or over three times the required matching funds.

However, the initial effort launched in 1963 has barely scratched the surface of need for community facilities. A few statistics, based on selected State mental retardation facilities construction plans (submitted in accordance with sec. 134, Public Law 88–164), will help to illustrate the extent of the need for such facilities.

We took some of the largest States simply because it was easier to use these as a basis for projection, and averaging their projected needs as specified in their construction plans, came up with a conclusion that the identified needs for construction in the country are in excess of $2 billion.

Our efforts to draw the retarded into the mainstream of community life have only begun. A tremendous job remains ahead of us if we are to provide the mentally retarded with the quantity and quality of service facilities they so desperately need.

Clearly the need for Federal support for the construction of community mental retardation facilities will far outdistance any amounts that are likely to be appropriated by Congress in the next few years. Therefore, we feel it would be presumptuous of us, and rather academic, to propose the particular figures, specify figures, that would be appropriate for these programs.

We feel that the determination on this is not going to be on the basis of need; it is going to be on the basis of budget, and we have to recognize this.

The amount already authorized for construction of community facilities for 1968 is $30 million. This, we know, is far less than could be used to good advantage; yet, the amount requested in the President's 1968 budget is only $15 million. We know this cut doesn't reflect any sense of less need on the part of the President's advisers but, rather, the budgetary stringency.

The first $5 million of any such appropriation must, under the law, be used to meet the minimum allotment provisions of section 132. In view of the unfortunate prospect that appropriations will be similarly restricted for the next several years, we respectfully suggest that the committee provide a somewhat less cumbersome basis for reallotment than that which is specified in the law, in order to permit suitable adjustments to be made more readily between the States, when some states are more immediately ready to use the funds than others.

We have situations in which a few States have not taken up their original allotments while there were states that could have used three or four times as much as they were permitted to have.

We also recommend that the factor of "need" which is mentioned in the allotment formula be understood to include recognition of the efforts any one State may be willing to make on behalf of mentally retarded military dependents who may require service while present in the State.

Last year the Congress very wisely passed legislation which permits the Department of Defense to pay the cost, the service cost, or part of the service cost, for caring for the retarded dependents of service personnel. One of the obstacles to proper use of this fund is the shortage of facilities throughout the country and especially in those States that may have major military installations.

The military medical benefits act permits the Department of Defense to reimburse any public agency for the operating costs, but it doesn't take care of the issue of construction.

There is continuing need to focus attention on those types of facilities for which other Federal agencies, in and out of the Public Health Service, cannot properly render aid. In this connection we wish to suggest an editorial change in the present language which could also have a significant psychological effect. We recommend that the term "custodial care,"—a phrase which is fraught with unpleasant connotations and which has been largely deleted from the language of the regulations for this reason—be eliminated and that the terms "day and residential care" be substituted. This would have no practical effect in a legalistic sense but would have quite a bit of effect in terms of interpretation of the program.

For the past several years NARC has actively advocated legislation to provide Federal assistance for the development of services in community mental retardation facilities. The need for such assistance was recognized as early as 1962 when the original facilities construction legislation was under consideration. As time has passed, the need for Federal funds to stimulate State and local activity has become more and more apparent.

We had hoped to come before this subcommittee today to express our unequivocal endorsement of the administration's proposal. Unfortunately, while we support the basic purpose of section 4 of H.R. 6430, we feel that the language used in this section is not well adapted to the purpose of stimulating the development of services in community mental retardation facilities.

The stringent limitations which the Vietnam conflict has placed on domestic spending make it all the more important that Congress authorize a program which will provide the maximum return from each Federal dollar invested. The administration proposal for staffing

mental retardation facilities is closely patterned after the Mental Health Centers Staffing Act and, as such, fails to take into account the distinct historical origins, purposes, and contents of the two separate construction programs. Since section 4 of the administration's bill is not designed to meet the particular needs of mental retardation facilities, inefficient allocation of Federal resources is likely to occur.

I think that the Surgeon General yesterday clarified rather well how the rather diffuse model or pattern or conceptualization that applies to the development of a range of services, an array of services, for the mentally retarded differs from the rather targeted and specific model that has been developed for the community health centers.

In our opinion the language used last year in section 8 of the Senate passed version of the comprehensive health bill (S. 3008) is far superior to section 4 of H.R. 6430. Bills similar to section 8 of S. 3008 have been introduced this year in both the House, where Congressman Waldie has introduced H.R. 5110, and in the Senate, where Senator Javits has introduced S. 389. We would like, however, to briefly outline our reasons for supporting H.R. 5110 in preference to section 4 of H.R. 6430.

In the first place, there is the question of types of costs covered. Obviously, any meaningful Federal aid program must cover part of the cost of staff salaries.

However, experience indicates that other operating expenses, such as transportation and rapidly depreciating equipment constitute a significant part of the cost of operating community programs for the retarded which can truly reach the clients most in need.

To cite a specific example: The report of a recent survey of day care centers in Wisconsin indicates that "mentally retarded individuals in areas served by 18 of the 23 centers are being denied the care and treatment which they need because of transportation problems." To limit all grants by statute to a percentage of salaries of professional and technical personnel might well deny aid entirely where it is most needed.

The problem of transportation arises in part because the programs we need most for the mentally retarded are ones which must be attended on a daily basis and ones which involve children who are frail and even perhaps physically handicapped, so that getting to and from the facility, whether it is in an urban area or a rural area, is one of the major concerns. Anyone who is familiar with school operations recognizes that transportation is a major factor in operating any daily program for children.

In fact, what happens is that the people who get to these centers when you don't provide transportation are from the families who can arrange it. So we believe it is misleading—no matter what percentage you specify—it is misleading if you are only allowing the Federal Government to share in the costs of salaries.

We also agree that there is tremendous need to develop new services, as referred to in the administration bill. However, in our zeal to begin new programs, we must not overlook the need to expand services which had been begun on a shoestring. In the search for novelty, we sometimes overlook the efficancy and importance of extending that which has been begun well.

A single funding mechanism to support the initiation and expansion and improvement of services would encourage innovation, but not

at the expense of consolidating efforts which have been satisfactorily begun but on too small a scale.

The experience of the Vocational Rehabilitation Administration with expansion and improvement grants has demonstrated the usefulness of such a funding mechanism, particularly where voluntary agencies have started programs on a shoestring which permitted only a marginal quantitative or qualitative level of operation.

In a few cases the objection has been raised that some new facilities are being constructed without regard to overall community planning. We would propose a provision which would enable the Secretary to assure himself that any service to be funded under proposed part D would not only add to existing services but would fill a definite need in the particular community.

Yesterday, there was some reference to the varying needs of communities, the fact that some already have some services and in some there is practically nothing, and we feel, and therefore, that it is important that the language of the legislation permit the kind of flexibility that permits the administering agency to assist in the initiation of services for which the community itself is ready.

We think that there is a need, in this connection, for flexibility in the matching formula. We have suggested that the language "up to 75 percent" be used. It is certainly not our expectation or intention that this be the matching ratio for all years, but we are aware of many different types of situations throughout the country where the amounts, the pattern of matching, should be adjusted to the local circumstances. A particularly disadvantaged community, for example, may need more than rapidly declining support for a period of 2, 3, or 4 years out of the 5.

We recognize that this is a program designed to initiate and not to sustain, and we accept that, but we feel that if it is to initiate the right programs somewhat greater flexibility is required.

While we spoke earlier in this testimony of the excellent response to the construction grant opportunity—the large amount of non-Federal money committed—we have to say that there is another side to this coin, and that in many instances the most needy communities, the highest priority projects have not come in, and this is partly a reflection of two things: Either the disadvantageous matching under the construction formula or the inability of that particular community to mobilize the initial operating support.

The rapidly declining mandatory matching percentage which was devised for the Community Mental Health Centers Act, we feel, is inappropriate in the case of mental retardation. A rapidly declining formula can be tolerated in the community health centers because they have a firmer expectation of receiving support from other sources, very important among which are the so-called third-party payments, such as medicare, medicaid, and hospital and health insurance, group insurance, and so forth, that many of the patients in community mental health centers can bring with them.

But these types of support are not generally available for the services which are most needed by the retarded, some of which do not classify as medical, and most of which services must be continued over a period of time which outruns most of these insurance programs.

We feel quite strongly in this connection that real efforts must be made to develop participation in funding on a long-range basis by State and local governments. It is not enough to depend on private funds.

We believe that the State and local government agencies should be actively encouraged to contribute to the long-range goals of mental retardation programs, and we suggest that language along the lines of that in H.R. 5110 would be useful in this connection, since it gives preference, preferably after July 1, 1969, or thereabouts, to programs which have some non-Federal public participation.

The reason we suggest that this provision not become active immediately is that we would like to give leeway to accommodate the usual legislative biennium for the State legislatures and permit them to respond and to act before it becomes operative.

We feel confident that a comparison on the provisions of so-called staffing or operating objectives of H.R. 6430 and H.R. 5110 will indicate to you that there are ways of improving on the language of the administration bill.

We would like to endorse most wholeheartedly the proposal to extend the university-affiliated facilities program. I believe the testimony given by Dr. Lee yesterday was most persuasive in this regard, and I will pass over that portion of our own prepared testimony excepting for one comment.

Much of the success, or much of the promise, of the university affiliated program for the last 3 years can be traced to the program planning grants which have been awarded to the universities in order to permit them to perform the necessary interdepartmental planning and organization which must precede the submission of a well-thought-out grant application.

These small amounts of planning money have paid off in the quality of the grant requests, in the Mental Retardation Branch (now Division) has been providing some of this planning money from its project grant funds under the old public health Law. Since the enactment of Public Law 89–749, categorical funds are no longer available for this purpose.

It is not clear to us, or to the people we have consulted, whether noncategorical health project funds, which are now controlled by the Office of the Surgeon General, will be made available for planning university affiliated programs. In view of the successful experience with these planning grants so far, we urge this subcommittee to elicit assurances from HEW that such program planning funds will be made available through some appropriate funding mechanism.

We also want to say for the record that we deplore the decision not to continue part A for a year or two longer. We have reason to believe that there are several highly eligible universities who would have taken advantage of this program had it been continued, and that this would have increased the diversity and the geographical distribution of these centers. We feel that this is probably a casualty of the Vietnam situation, which we can only go on record as viewing with great regret.

I do want to thank the committee most warmly for its interest, and I hope that we may soon see a bill reported out and that the success which has thus far attended this program will be continued and sustained.

Thank you.

(Dr. Bogg's prepared statement follows:)

STATEMENT OF DR. ELIZABETH M. BOGGS, REPRESENTING THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

I. Introduction

The National Association for Retarded Children is a nationwide voluntary association dedicated to the twin goals of preventing mental retardation and ameliorating its tragic effects. We speak for the "consumers of services" who, in the case of the mentally retarded, are usually unable to speak for themselves. Our concern extends to the mentally retarded of all ages and all degrees of disability.

Our members are found in every state of the union. Although we do not have the sophisticated machinery for massive data gathering available to federal and state governments, we are in touch with the needs of the retarded in a very direct way through our network of 1100 local member units.

Mental retardation affects the lives of millions of our citizens and causes annual economic losses totalling billions of dollars. Against this background the few million dollars of annual expenditure called for in the legislation before us seems almost inconsequential.

These and other federal expenditures can, however, have an impact out of proportion to their size if wisely spent. The potential impact of PL 88–164, the Mental Retardation Facilities Construction Act of 1963, is already apparent. We are here today seeking your action to reinforce and enhance that potential.

That federal aid is needed and could be well expended in vastly larger amounts than already contemplated, few will deny. However, we do not come today asking for money which cannot be found during this period of fiscal stringency now facing our nation. Rather, we ask of the Congress and the Administration that what has been well begun be still more effectively continued, that planful approaches be consistently supported, that the legitimate expectations of the state and community agencies be realized, that the highest priorities be attached to the greatest needs, and that artificial barriers to the most efficient utilization of funds be removed. Although our experience with the 1963 legislation is still short, and our conclusions therefore tentative, it appears that the provisions of the original statute should be somewhat amended as well as extended.

A well-managed federal attack on the problem of mental retardation must involve a variety of agencies within the Department of Health, Education, and Welfare as well as certain other departments. Education, Rehabilitation, and Welfare must play their appropriate parts along with the Public Health Service. We seek to develop, over the shortest feasible period of years, adequate authority in each of these federal operating agencies to cover formula and project grants in support of services, grants for continued planning, for research and demonstration, for professional training, and for construction.

II. Extending and Amending the Authority for Construction of Community Mental Retardation Facilities

A. *Authorized Appropriations.*—The Report of the President's Panel on Mental Retardation (October 1962) stresses the need to develop a full range of services for mentally retarded children and adults in or near communities where clients and their families reside. This emphasis on community-oriented programs has revolutionized society's thinking about mental retardation and has become a basic tenet of our modern philosophy of care and habilitation of the mentally retarded.

After examining the adequacy of community mental retardation facilities, the President's Panel concluded that "there is a shortage of physical facilities for many types of needed programs for the retarded, including classrooms, workshops, 'activities centers,' day care, half-way houses, and full-scale residential care" (p. 141, Panel's Report). In the area of day and residential facilities alone the Panel found a need for over 200,000 places in 1962. Current data indicates that this is a serious understatement of the need (see below).

The Department of Health, Education, and Welfare, in response to the Panel's report, sponsored legislation in 1963 to assist in the construction of community facilities for the mentally retarded. The resulting program, authorized under Part C, Title I, PL 88–164, has induced state and local public and voluntary agencies to take the first tentative steps toward developing a network of community mental retardation facilities.

It is well to recall that, unlike the Community Mental Health Centers Construction Act, Part C of PL 88–164 was originally proposed because both the Public Health Service and the President's Panel on Mental Retardation recognized that many of the most urgently needed facilities for day and residential

care and habilitation of the retarded could not be funded through the authority granted to the Hospital and Medical Facilities program or any other existing federal construction authority. New legislative authority was required for this purpose.

During the three years this program has been in operation, communities have provided tangible evidence of their willingness to respond to federal leadership. Indicative of this grass roots interest is the amount of non-federal matching funds which have been raised for the 106 projects approved under this program as of March, 1967. For these projects public and non-profit agencies at the state and local level have provided $58.4 million, or over three times the required matching funds.

However, the initial effort launched in 1963 has barely scratched the surface of need for community facilities. A few statistics, based on selected state mental retardation facilities construction plans (submitted in accordance with Section 134, PL 88–164), will help to illustrate the extent of the need for such facilities:

TABLE I.—*Estimated cost of constructing community facilities for the mentally retarded in 4 selected States*

State	Total number of mentally retarded needing service	Estimated cost of construction [1]
California	[2] 35,043	$215,864,880
New York	[3] 36,229	223,170,640
Ohio	[3] 17,348	106,863,680
Pennsylvania	[3] 27,999	172,473,840
Total, 4 States	116,619	718,373,040
U.S. projected estimate	384,000	2,360,000,000

[1] Calculated on the basis of an average per client cost of construction of $6,160 for all types of pt. C facilities. This figure was arrived at by dividing the total cost of the 106 pt. C projects approved as of Mar. 1, 1967, by the estimated total number of additional mentally retarded persons who will be served in these projects ($75,200,000÷12,500).

[2] Based on 1966–67 mental retardation construction plan.

[3] Based on 1965–66 mental retardation construction plan.

Our efforts to draw the retarded into the mainstream of community life have only begun. A tremendous job remains ahead of us if we are to provide the mentally retarded with the quantity and quality of service facilities they so desperately need.

Clearly the need for federal support for the construction of community mental retardation facilities will far outdistance any amounts that are likely to be appropriated by Congress in the next few years. Decisions on the amounts to be appropriated will be based more on budgetary consideration than on actual need. Therefore, it would be presumptuous and highly academic for us to propose future authorization for Part C programs; however, we urge this Subcommittee to carefully scrutinize the clear evidence of need for community mental retardation facilities and authorize amounts which are realistic in terms of the task before us.

B. *Proposed Amendments to Part C, Title I, PL 88–164.*—The amount already authorized for construction of community facilities for 1968 is $30 million, far less than could be used to good advantage; yet, the amount requested in the President's 1968 Budget is only $15 million. The first $5 million of any such appropriation must, under the law, be used to meet the minimum allotment provisions of Section 132. In view of the unfortunate prospect that appropriations will be similarly restricted for the next several years, we respectfully suggest that the Committee provide a somewhat less cumbersome basis for reallotment, in order to permit suitable adjustments to be made more readily between the states. We also recommend that the factor of "need" be understood to include recognition of the efforts any one state may be willing to make on behalf of mentally retarded military dependents who may require service while present in the states.

There is continuing need to focus attention on those types of facilities for which other federal agencies, in and out of the Public Health Service, cannot properly render aid. In this connection we wish to suggest an editorial change in present language which could also have a significant psychological effect. We recommend that the term "custodial care" in Section 401 of PL 88–164 be deleted and the words "day and residential care" substituted.

III. Federal Assistance for the Development of Services in Community Mental Retardation Facilities

For the past several years NARC has actively supported legislation to provide federal assistance for the development of services in community mental retardation facilities. The need for such assistance was recognized as early as 1962 when the original facilities construction legislation was under consideration. As time has passed, the need for federal funds to stimulate state and local activity has become more and more apparent. Now, five years later, the Administration is finally sponsoring long awaited legislation to enact a federal grant program in this area.

We had hoped to come before this Subcommittee today to express our unequivocal endorsement of the Administration's proposal. Unfortunately, while we support the basic purpose of Section 4 of H.R. 6430, we feel that the language used in this section is not well adapted to the purpose of stimulating the development of services in community mental retardation facilities.

The stringent limitation which the Vietnam conflict has placed on domestic spending makes it all the more important that Congress authorize a program which will provide the maximum return from each federal dollar invested. The Administration proposal for staffing mental retardation facilities is closely patterned after the Mental Health Centers Staffing Act (Part B, Title II, PL 89–105) and, as such, fails to take into account the distinct historical origins, purposes and contents of these two separate construction programs. Since Section 4 of the Administration's bill is not designed to meet the particular needs of mental retardation facilities, inefficient allocation of federal resources is likely to occur.

In our opinion the language used last year in Section 8 of the Senate passed version of the Comprehensive Health bill (S. 3008) is far superior to Section 4 of H.R. 6430. Bills similar to Section 8 of S. 3008 have been introduced this year in both the House (H.R. 5510—Waldie) and the Senate (S. 389—Javits). These bills would authorize a five-year project grant program to support up to 75% of the cost of initiating, extending, or improving services in community mental retardation facilities. Appendix I contains a comparative analysis of the provisions of Section 4, H.R. 6430 and H.R. 5510 (S. 389). We would like, however, to briefly outline our reasons for supporting H.R. 5510 in preference to Section 4 of H.R. 6430:

1. *Types of Costs Covered.*—Obviously, any meaningful federal aid program must cover part of the cost of staff salaries; however, experience indicates that other operating expenses, such as transportation and rapidly depreciating equipment, constitute a significant part of the cost of operating community programs for the retarded which can truly reach the clients most in need. To cite a specific example: The report of a recent survey of day care centers in Wisconsin indicates that "mentally retarded individuals in areas served by 18 of the 23 centers are being denied the care and treatment which they need because of transportation problems." To limit all grants by statute to a percentage of salaries of professional and technical personnel might well deny aid entirely where it is most needed.

2. *Expansion and Improvement of Services.*—We certainly agree that there is a tremendous need to develop new community mental retardation services throughout the nation. However, in our zeal to begin new programs, we must not overlook the pressing need to strengthen and expand services which are now available on a limited basis. A single funding mechanism to support the initiation, expansion and improvement of services would encourage innovation but not at the expense of consolidating efforts which have been satisfactorily begun but on too small a scale. The experience of the Vocational Rehabilitation Administration with expansion and improvement grants has demonstrated the usefulness of such a funding mechanism, particularly where voluntary agencies have started programs on a shoestring which permitted only a marginal quantitative or qualitative level of operation.

3. *Eligible Services.*—In a few cases the objection has been raised that some new facilities are being constructed without regard to overall community planning. Under the provisions of H.R. 5510, the Secretary would be required to assure himself that any service to be funded not only adds to existing services but fills a definite need in the particular community.

4. *Development of Community Services.*—H.R. 5510 would permit a community—even the most underdeveloped community—to start where it is and initiate the service or services for which the community is most ready. It does not require the community to provide all types of services at once.

5. *Flexibility in Federal Matching.*—H.R. 5510 would permit the Secretary to exercise administrative discretion in establishing the federal matching percentage

(up to 75%) depending on the circumstances involved in the particular grant request (e.g., the amount and duration of support available from non-federal sources). Thus, maximum assistance could be offered to the most needy communities without excluding some aid to those which already offer a few services. One of the lessons which can be drawn from our experience thus far with facilities construction grants is that the communities most in need of programs for the retarded are frequently slow to submit grant applications. Grant programs, therefore, should be designed to provide additional aid, when necessary, to the most backward communities.

H.R. 5510 does not presuppose (as does the Mental Health Staffing Act) that a community facility always can become rapidly self-sufficient to the point of maintaining itself out of "third party" payments such as medicare, medicaid, and health and hospital insurance. These sources of income are not generally available for the services most needed by the retarded, many of whom require years of attention on a daily basis.

6. *Duration of Federal support.*—H.R. 5510 permits grants to extend "up to 5 years." Experience with Section 3 of the Vocational Rehabilitation Act (prior to 1965) showed that, where the retarded are involved, the benefits of a program take longer to demonstrate and the premature withdrawal of federal funds (and related consultation) can result in the collapse of the demonstration project. The use of administrative discretion in both percentage of matching and duration of assistance can be a real asset in the highly fluid situation with which we are faced around the country. This is particularly true in view of the fact that we do not, as yet, have any assurance that federal formula grant support will become available to mental retardation facilities, although such support is authorized for both rehabilitation programs and mental health centers.

7. *Allotments.*—The program called for in H.R. 5510 would be administered on a project grant basis without state allotments. At this stage in the development of community mental retardation services, a project grant program would permit optimum deployment of appropriated funds. Experience indicates that allocating small amounts in a largely untested field by means of a formula grant frequently leads to inequitable and inefficient distribution of resources. This result is especially likely in the case of services in mental retardation facilities since the states are at such different stages of readiness for assistance in meeting the cost of initiating and extending programs in these facilities.

8. *Participation by State and Local Governments.*—There is a great need to develop reliable long range funding sources at the state and local level for community mental retardation programs. H.R. 5510 would encourage state and local governmental agencies to contribute to the long term financial stability of mental retardation programs by giving preference to programs which are receiving non-federal public funds in future years.

For the reasons indicated above, we urge this Subcommittee to carefully analyze the relative merits of H.R. 5510 and Section 4 of the Administration bill. By doing so we feel confident that you will agree with us that H.R. 5510 is much better suited to the unique requirements of a program of initial support for services in community mental retardation facilities.

IV. Extending the Authority for Construction of Mental Retardation Research Center

NARC feels that the Administration has acted unwisely in not proposing the extension of the Mental Retardation Research Centers Construction Program, authorized under Part A, Title I of PL 88–164. In our opinion, the objectives of this program have not been fulfilled in the four years it has been in operation.

V. Extending and Amending the Authority for Construction of University Affiliated Facilities for the Mentally Retarded

NARC wholeheartedly endorses the Administration's proposal to extend the University Affiliated Facilities Construction Program.

The evidence of need for competent, professionally trained personnel to work with the mentally retarded is overwhelming. We must give high priority to recruiting and training professionals in this field; otherwise our efforts to develop programs, facilities and services for the mentally retarded will be fruitless.

The location of a full range of services for the mentally retarded within the academic atmosphere of a university provides an ideal setting for broad ranged, interdisciplinary training in mental retardation. The opportunity for first hand

[1] Thus far, the construction of 12 research centers has been funded under this authority.

contact with mentally retarded patients and the cross fertilization of ideas between the various service disciplines which is offered in university affiliated facilities are of inestimable value in preparing students for their later careers.

We support the Administration proposal to amend Part B to permit research related or incidental to activities in university-affiliated facilities. Universities provide the traditional setting for research activities. Therefore, we should be careful not to erect unnatural barriers to creativity. Explicit authority to permit research adjunct to the service and training programs of university facilities seems well advised.

In addition, NARC supports the inclusion of individuals with "other neurological handicapping conditions" in university affiliated programs. One of the major purposes of these facilities is to prepare students for the types of experiences they will encounter later in their careers. The inclusion of individuals with other neurological handicapping conditions, which are often encountered in the same treatment facilities as the mentally retarded, will provide a broader training experience for the students in the program.

Much of the success of the university affiliated program over the past three years can be traced to the program planning grants which have been awarded to universities in order to permit them to perform the necessary interdepartmental planning and organization which must precede the submittal of a well thought out grant application. These small amounts of planning money have paid off in terms of the quality of the grant requests which have been submitted. Up until recently the Mental Retardation Division has provided this planning money from its project grant funds. Since the enactment of PL 89–749 categorical funds are no longer available for this purpose. It is not clear if non-categorical health project funds, which are now controlled by the Surgeon General's Office, will be made available for planning university affiliated programs. In view of the successful experience with these planning grants thus far, we urge this Subcommittee to elicit assurances from HEW that program planning funds will be made available through some appropriate funding mechanism.

In conclusion, NARC asks this Subcommittee to keep in mind that the success of our continuing efforts to draw the mentally retarded into the mainstream of community life and offer them the opportunity to develop to the maximum of their potential will depend in no small measure on the development of adequate sources of federal support to stimulate and guide activity at the state and local level.

We would like to express our sincere appreciation for the opportunity to appear before this Subcommittee today to offer our views on pending legislation to amend and revise the Mental Retardation Facilities Construction Act.

APPENDIX I.—*Federal assistance for the development of services in community mental retardation facilities, a comparison of sec. 4 of administration bills (H.R. 6430; S. 1099) with bills supported by the National Association for Retarded Children (H.R. 5110 and S. 389)*

	H.R. 6430–S. 1099	H.R. 5110–S. 389	NARC comments
Purpose	To assist in meeting initial cost of professional and technical personnel for community mental retardation facilities.	To assist in initiating, extending, or improving services in community mental retardation.	Basic purposes are similar, but S. 389 (H.R. 5110) focuses on the costs of providing a service rather than on 1 component of such costs (i.e., staff salaries).
Types of costs covered	Costs of employing professional and technical personnel.	Same, plus other costs established by the Secretary (HEW) pursuant to regulations.	S. 389 (H.R. 5110) recognizes that significant costs other than personnel are involved in operating many community mental retardation services (e.g., transportation costs may comprise 25–30 percent of the budget of a day care program).
Duration and Federal share in any 1 grant.	Limited to 51 months; Federal share: 75 percent 1st 15 months; 60 percent next 12 months; 45 percent next 12 months; 30 percent last 12 months.	Limited to 5 years; Federal share would vary according to the circumstances but could not exceed 75 percent.	To accommodate the variety of situations among States and within a given State, a project grant authority is needed with some discretionary flexibility in matching—up to 75 percent. The sharply declining matching specified in H.R. 6430 repeats the formula of the Community Mental Health Staffing Act (Public Law 89–105); it anticipates a rapid escalation in non-Federal support. Community mental health centers can anticipate substantial income from "3rd party" payments (medicare, medicaid, health and hospital insurance). Such payments are not generally available to cover the kind of services or duration of individual need which will characterize many community mental retardation facilities. Also Federal-State formula grant money earmarked for mental health under Public Law 89–749 is expected to be targeted on community mental health centers by the State agencies. Such funds are not necessarily available for extending mental retardation services.
Eligible facilities	1. The facility must be public or nonprofit. 2. "Mental retardation facility" is already defined in sec. 401 of Public Law 88–164 as "a facility for the diagnosis, treatment, education training or custodial care of the mentally retarded".[1]	1. Same. 2. Same.	
Eligible services	Eligibility limited to: (*a*) facilities which were constructed with Federal assistance under pt. C, title I, Public Law 88–164; or (*b*) an entirely new service in an existing facility.	The initiation, extension or improvement of a service could be supported if the Secretary found that such a service was: (*a*) necessary and basic; (*b*) needed in the particular community; and (*c*) could not be supported through another Federal grant program.	Need in field of mental retardation is not only for new types of service but for extending services which are now available on a limited basis. Often it is more economical and feasible to expand or improve an existing service than to initiate an entirely new one (N.B. the successful experience of the Vocational Rehabilitation Administration with expansion and improvement grant provides a noteworthy precedent).

See footnotes at end of table, p. 78.

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APPENDIX I.—*Federal assistance for the development of services in community mental retardation facilities, a comparison of sec. 4 of administration bills (H.R. 6430; S. 1099) with bills supported by the National Association for Retarded Children (H.R. 5110 and S. 389)*—Continued

	H.R. 6430–S. 1099	H.R. 5110–S. 389	NARC comments
State and local government participation.	No specification	After July 1, 1968 [2] preference would be given to facilities supported in part by State or local public funds.	There is a great need for continuing public support of mental retardation services due to the chronic nature of retardation. The "preference" clause of S. 389 (H.R. 5110) will encourage State and local government agencies to contribute to the long term financial stability of programs to be developed in mental retardation facilities.
Maintenance of effort	Secretary must be satisfied that Federal funds will increase (and in no case supplant) the level of State, local and other non-Federal funds.	Same.	
Conformity to the State plan	Must be consistent with the State mental retardation services plan, if one is in existence.	Same.	
Allotments	Appropriations must be allotted among the States on the basis of a formula which takes into account variations in need for services, population and per capita income.	Appropriations distributed on a project grant basis.	Experience with allotting small appropriations in a largely untested field indicates that this approach leads to inefficient and inequitable distribution. This would be especially true in mental retardation, since we know that States are at different stages in developing programs and facilities and therefore have varying needs for critical assistance in any one year.
Authorizations	$7,000,000 in fiscal year 1968; necessary sums (as authorized by Congress, over the next 7 fiscal years for initial and continuation grants.	$7,000,000 in fiscal year 1968; $12,000,000 in fiscal year 1969; $15,000,000 in fiscal year 1970; $15,000,000 in fiscal year 1971 and necessary sums (as authorized by Congress) for the next 4 years.	The need far outruns any appropriations which are likely to be authorized in the next few years. NARC would prefer a "such sums as may be necessary" clause for 1969 and thereafter, but respecting congressional preference for specific authorizations, recommends not less than $15,000,000, $20,000,000 and $30,000,000 for fiscal years 1969–71.

[1] NARC recommends that "custodial care" be amended to read "day and residential care."

[2] Should be changed to "1969" in order to permit the States time to conform to this requirement.

Mr. SATTERFIELD (presiding). Thank you, Dr. Boggs. I have one brief question. You recommend, apparently, that rather than grants for staffing purposes on a descending contribution scale on behalf of the Government that there be a flat amount up to 75 percent in each year up to a 5-year period?

Dr. BOGGS. The term "up to 75 percent" is a critical term. We do not propose that all grants be made at 75 percent for each of 5 years. We would anticipate that there would probably be some administrative mechanism for creating a descending approach.

For example, in a comparable situation under the Vocational Rehabilitation Act, they have a provision for 90 percent in the first 3 years and 75 percent in the last 2.

We do not think that a formula of that kind should be written into the statute at this point, partly because the kind of declining formula you have in the Mental Health Centers Act invites everybody to try to meet exactly that.

We foresee certain circumstances in which a particular community the maximum need will come in the second year, the maximum need for assistance, and that after that one can have a decline.

We know that in some States there are already funds available from other public sources which would make 75 percent unnecessary even in the first year.

So we are appealing, in view of the small amount of money that is likely to be appropriated, for an authority which permits the greatest discretion at the administrative level. The small amount of money that is available has got to be spent to the best advantage; if the amounts to be appropriated were much larger we could see merit in a more stringent approach by the Congress.

But this is an experimental program, and we are entering on it for the first time.

You, in accordance with your practice, will probably require that this legislation come back for review in a relatively short period of time, maybe 3 years. We would ask that you permit some discretion, administrative discretion, in this matter, and if it is not to your liking, you will certainly have a chance to review it in very short order.

Mr. SATTERFIELD. In that connection, you made a point that there are not third-party contributions in this area that we find in the mental health facilities. Do you feel that the normal facility we are talking about here would be in a position where it could carry the full load for staffing after 5 years if we proceeded on the basis that you suggest?

Dr. BOGGS. No, I do not. I think that the local facility of itself and out of its own resources could not. I think it is extremely unlikely. But what we are working on here is building a pattern of long-term stability with funds from sources other than Federal, and this requires time in which to work out the State and county support patterns which are beginning to become apparent around the country but which have not taken root yet, and particularly have not taken hold in those States which are the most laggard in implementing this kind of program.

We need more time for experimentation. There is another reason why we need time. You know that under the Vocational Rehabilitation Act and under the Public Health Service Act, 89–749, the Federal Government makes formula grants available to certain State agencies which permit them, in combination with their own State tax

funds, to, in turn, help to support, on a discretionary basis, community programs of various desirable kinds.

Under the Public Health Act of last year, 15 percent of the health formula money is available to departments or divisions of mental health. This is not a "categorical" division. It is an administrative division. We don't know yet whether the health departments or the mental health departments will choose to use these funds in a significant way on behalf of the mentally retarded.

In another 5 years, or maybe 3 years, we may know about these alternative means of support.

But quite frankly the nature of mental retardation, the long-term need of each individual, really means that we must have public participation in the support of programs. It cannot be left to either third-party payments, patient fees, or voluntary support through public contributions.

Mr. SATTERFIELD. In essence, are you advocating that once the Federal Government starts this program it should continue it?

Dr. BOGGS. No, I think this is a misinterpretation of our position. As far as this legislation is concerned, we recognize this is something to get local programs off the ground. If it is to do that effectively, we feel there must be more flexibility in this 5-year period.

When the Vocational Rehabilitation Administration was administering grants for sheltered workshop services, they originally had a 3-year project authority, and it wasn't enough to really get things launched, and they got that extended to a maximum of 5 years for any particular project, and as a result we can now foresee a more efficient transition from the initial funding to a long-term funding.

Mr. SATTERFIELD. I have one other question. In your proposal for project grants, do you intend that those grants be made only for new services?

Dr. BOGGS. No. We believe—here again—that services in community mental retardation facilities need to be extended and expanded and improved. We concur wholeheartedly with the clauses that it is traditional for the Congress to include concerning maintenance of effort, and the proviso that no Federal funds can be used to replace any funds that would otherwise have been spent from public or private sources. We are entirely in agreement with that.

But we can easily see a situation in which a fairly substantial community you have one small group of children cared for and you want to have two groups of children cared for with the same type of service, and you need something to get that second group started.

Surely we need innovation, but everything we need is not—new. We need some improvement and some extension, and in some of these instances where programs have been initiated by volunteer organizations, they have come in almost at a substandard level, and we would like to be able, for example, to add a more sophisticated staff member to a project that is already underway, and demonstrate that this really makes it more worth while, and then come back in with the long-term support from the State and local sources.

It is a question of flexibility and the question of getting the maximum leverage.

Mr. SATTERFIELD. Thank you.

Mr. Brown?

Mr. Brown. I would like to pursue, Dr. Boggs, so I can see what Mr. Satterfield was trying to understand also, I believe, about the 75 percent, and the variation of services that would be covered by Federal grants.

Now, is it your ambition to spread the supportive Federal grant program longer than 5 years or, rather, to not tie it down to the 75–60, 45–30 arrangement?

Dr. Boggs. The objective is not to try to tie it down to the 75–60, 45–30. We do not anticipate that there would be a grant renewal for any of these projects.

In other words, any projects which received a 5-year grant, that support would terminate at the end of 5 or less years, depending on what was determined at the outset. Some people only need 3 years' support, and that is all they should get.

But we could anticipate that a given facility might, for example, come in at a later date for an additional grant for another purpose, for still some other extension, improvement, initiation, or what have you, but they would not be permitted to apply simply for an extension of support, Federal support, for the existing project.

If that were permitted, we would get the Federal Government into a sustaining support program through the project grant mechanism, which I think is a contradiction in terms.

Mr. Brown. Do you think it would be possible to write this in in such a way that you would average out the support over a 4- or 5-year period to 50 percent?

Dr. Boggs. I think it would be a mistake to average out the support for any particular project to 50 percent, because one of the objects here is to——

Mr. Brown. Are we understanding each other, because what I have done here is put 75–60, 45–30, and divide it by 4.

Dr. Boggs. Yes, I think so. You are saying let them choose 60 the first 2 years and 40 the next 2 years, and it would average out. That would be a little less rigid than we have now. But there are communities which have not come in and have not moved because they are so lacking in resources that to say you have got to match 50 percent over the next 5 years will simply not get them off the ground.

On the other hand, there are other communities which could move on basis of an average of 25 percent over the first 4 years.

Mr. Brown. In other words, you would vary this from community to community, and perhaps as one community is offered 75 percent for the 3 or 4 years——

Dr. Boggs. I think it is only fair to indicate your intention to terminate toward the end of the project, I would agree to that, but I think the rate that this is applied should be adapted to the individual community's circumstances.

We indicated that there is a great difference within many States, in the capacities of the given communities to come forward, and what is happening is that the "have" communities are coming forward and taking the construction money, because the "have not" communities are saying, "Even if we could put up money for construction, we don't have the money to operate."

Mr. Brown. On that point, and I got this inference yesterday from something Dr. Lee or one of the other gentlemen made reference

to: Is there any correlation between the economic level of a community or a State and the incidence of mental retardation?

Dr. Boggs. Yes. You were pursuing yesterday with considerable acumen the whole question of impact of cultural deprivation on the incidence of mental retardation, and the answer to your question is that mild mental retardation occurs more frequently in areas which are socially and economically deprived.

The incidence of moderate, severe, and profound mental retardation is approximately constant. That is, it is approximately independent of those factors.

However, we were not basing our arguments here primarily on the fact that there might be a greater need in terms of people in these communities, but rather on the fact that the community itself doesn't have either the economic resources or the ideational resources, the initiative, the leadership, to mobilize itself to qualify for a grant program of this sort, as does the more privileged community.

Mr. Brown. If I can be specific, I notice there is nothing in the map for the State of Mississippi.

Dr. Boggs. There is a slightly different reason, and that is that the State of Mississippi decided not to avail itself of this construction program.

Mr. Brown. I am sorry you said that, because Mississippi is a low-income State in comparison to some other States that seem to have gotten going on this situation more rapidly.

Are we likely to find a higher percentage of retardation in the State of Mississippi because there is less——

Dr. Boggs. Opportunity, yes.

Mr. Brown (continuing). To finance locally the clinics you are talking about, and therefore a greater need for this Federal participation?

Dr. Boggs. I would say by the standards of the Nation as a whole, the prevalence of mild retardation in Mississippi is higher, and I think this has been shown by the Selective Service statistics.

Mr. Brown. I wonder if you could provide any other statistics directly related to mental retardation?

Dr. Boggs. The reason I say this, one of the grounds for rejection that has been separated out has been the mental functioning level, and this was brought out rather strongly in the postwar study of the World War II recruitment.

Mr. Brown. I am still not completely clear, or perhaps the word I should use is "satisfied," about the 89 percent of mild retardation, as to whether or not this is in fact retardation or merely underdevelopment, and I think there is a line here that——

Dr. Boggs. You are absolutely right. What you have been adverting to, both yesterday and today, is a subject which it is very difficult for professional people to describe adequately, because it is in in fact a situation in which there is overlapping and not-too-clear dividing lines, but let me reiterate something that was said yesterday:

If a child that might be born with potential in the normal range is, in early childhood, not exposed to stimulating experiences, and this goes on for a sufficiently long period of time, an irreversible failure to develop will characterize that child.

Now, the term is "irreversible."

Mr. Brown. I would say that is a key word.

Dr. Boggs. Yes. This is one of the reasons that so much emphasis is being placed on preschool programs, Headstart and so forth. The idea is to pick the children up early enough and enrich their environment.

Now, the degree of developmental deprivation, shall we say, which occurs in these cases is only partial, and that is why it adds mostly to the prevalence of mild mental retardation. It is less likely to make the child completely nonfunctional.

However, we can illustrate by another analogy: If you take a kitten, or for that matter a baby, and bring him up in the dark, he doesn't develop vision. By the same token if you take a human child and bring him up in the dark intellectually, he will not develop intelligence, and, just as with a creature who is kept in the dark as an infant, the organism can be deprived for a short period of time without doing permanent damage, but there is a critical period of time after which, if it is exceeded, you will never be able to reclaim that organism fully, whether it is a kitten or a child, or something else. There are certain analogies between these physiological facts and the intellectual and neurological development of children, but it is not possible to say we have a compartment here, and this is exactly where educational deficiency stops and true mental retardation begins because some of the changes, some of the depressed functions you see in people who test as mentally retarded may be remediable, and some may not be.

In the same individual this may be true.

Mr. Brown. That has been very helpful.

Dr. Boggs. To come back to Mississippi, if I may, I would think that under the program that is being discussed here, of project grants for the support of extended improved or new services, that grants could be made to particular facilities in Mississippi without reference to the nonesxitence of the state construction plan.

Mr. Brown. Let me ask you one other question: Did I understand your reference to the needs of service-affiliated retarded youngsters——

Dr. Boggs. You mean military service?

Mr. Brown. Yes, military service—to be suggesting a kind of impacted school district idea here?

Dr. Boggs. You have made a very correct analogy or allusion. I would hesitate to suggest that we write in any formulae, because the total amount of money we are talking about here is so amall. But it seems to me that if in its report, the committee would suggest that some attention be given to this problem in the assessment of "need," which is specified in the existing legislation as being one of the factors that must be considered in the allotment to the States—I am taking about construction money now—if the committee would direct the Public Health Service to introduce a factor relative to this I think that something could be worked out which could be administered.

Mr. Brown. Are you suggesting a specific factor other than consideration of the problem?

Dr. Boggs. I am not suggesting that you should try to write this out in detail.

What we want to do here is to encourage the States to construct—to make available the facilities they have, or that they will construct, across the board both to their own residents (let's say people who

have met durational residence requirements) and to the military dependents who require the services, whose families are located in that vicinity. There is a certain reluctance to do this now on the grounds that the taxpayers of State X have put up the money to construct the day care center, or whatever, and why should we accommodate these people who are only here for a short time?

As I said, the payment for the cost of the service is now available from DOD; it is just a question of the facilities.

Now, in fact, we know that certain States are federally impacted, as you pointed out, to a greater extent than others, and that they will have military personnel within their boundaries in the distant future as well as in the immediate future, and I think if they could be encouraged by receiving some additional Federal allotment under part C, in exchange for undertaking to be nondiscriminatory in their admission policies that this would be desirable.

Mr. BROWN. This raises another question of information which I would like to get from you if it is possible to provide it.

Mr. Chairman, I would like to ask if your agency can provide some summary or factual information on the methods by which public support other than Federal is coming to retarded facilities in the various States.

Dr. BOGGS. That is a tall order, because the States vary so widely but tremendous support is forthcoming.

Mr. BROWN. My inquiry relates to whether it is coming through the public school program in the States because that seems to me would help resolve to some extent the problems you have raised.

Dr. BOGGS. You are talking about the military now?

Mr. BROWN. I am talking about the impacted school districts.

Dr. BOGGS. This legislation we are discussing here today has by virtue of its legislative history been considered not to apply to public schools.

In other words public schools have been considered ineligible under this act here, and last year the Congress passed a very forward-looking provision in the Elementary and Secondary Education Act, referred to in our vernacular as title VI of that act, for the encouragement of public school programs for the handicapped.

Now generally speaking, the problem of a handicapped child, a retarded child, attending a public school in the vicinity of a military base, generally speaking this is no great problem because in part they get the impacted area aid and also because States do not in general enforce durationed residence requirements with respect to public schooling.

But the major thrust of this legislation (Public Law 88–164) must be directed toward, for example, day care facilities for children who are so very handicapped that they don't go to public school, for the adults that you were referring to yesterday who remain dependent or semidependent as adults, and to needs of this kind, for which there is not a complete network of support as there is for the public school program. For these programs there may very well be residence requirements so far as State funds are concerned.

The most critical concern with respect to the military dependents at this point is for residential care. From 90 to 95 percent of the space available for the residential care of the mentally retarded in this country is under the auspices of the States, and if you rely on private

resources you rely on resources which are either very, very costly, or which may be of dubious quality, because we do not have adequate quality control at present in all States.

The military family is required under the law to look first to the public facility, but if the public facility has a waiting list of a thousand, and if people have been on the waiting list for 2 or 3 years and the military family has just arrived, they are at the bottom of the list——

Mr. BROWN. I would like the information, and I have one final question.

You indicated you regretted the termination of part A of this program because so many adequate universities had expressed an interest in it.

Dr. BOGGS. I won't say a large number, but some.

Mr. BROWN. My thought is whether you regret it because of the need to support these universities, or whether the program has been established as needing more facilities for the mentally retarded.

Dr. BOGGS. I would say this. The Surgeon General said yesterday, "Let's take a breather and see what happens to these centers."

I think this is a rationalization in view of the fiscal stringency, for this reason: We don't anticipate the indefinite multiplication of these centers. Nevertheless, the 11 or 12 grants that have been made to date—there have been 11 for construction and one for equipment only—the protocols for these individual centers are very different.

They are not replicas of one another. They have different research focuses, different objectives. Some are primarily in the biological area, some in the——

Mr. BROWN. From the research standpoint, I think that might be desirable.

Dr. BOGGS. It is desirable, but frankly we feel that the potential for this diversity hasn't been fully exploited yet. Some universities anticipating that this program would be extended (which was not unreasonable of them to have assumed 2 years ago) have invested considerable thought and effort in the idea that they would like to prepare themselves, and we now get to the point where we say, "Sorry, boys, your interest was laudible, but it is futile."

This has a certain negative effect on the research community. Another factor that enters is that due to some of the freezes on construction funds, some of the centers that were awarded were told that they would have to defer their construction awhile. They then were confronted with an increase in the costs, and so some of these centers are not getting quite as much for the dollars they were allotted as they had hoped.

Some of them had hoped to come back and get supplemental grants for equipment.

So in a sense this thing has been cut off just a little prematurely. We recognize that we are dealing with factors that are beyond the control of the people who are interested in health, education, and welfare, but we feel for the record we should indicate to you people that this is not a planned curtailment in this area.

Mr. BROWN. Thank you. I think your remarks in that area were very generous.

Thank you, Mr. Chairman.

Mr. JARMAN (presiding). Dr. Boggs, one thing I want to add to the record is our appreciation of your association's recognition of the

budget requirements and of the demands of Vietnam and the resulting limitation under which we must all operate on domestic programs. I thought you expressed that well, and we appreciate the understanding.

Dr. Boggs. Thank you very much, and I would like to express one more word of appreciation, if I may. The construction program was initiated and initially administered by the hospital and medical facilities division of the Public Health Service, and it has just recently been transferred to the division on mental retardation.

The people in DHMF were confronted in 1963 with something quite novel to them, which necessitated their becoming familiar with needs they did not know about from their past experience.

They went after the new problems with a great deal of zeal. They prepared some good publications and one was on the design of facilities. I want to mention that in view of Mr. Scheuer's remarks yesterday. I want to give credit to Dr. Haldeman and Dr. Graning and their staffs. I also want to express appreciation once again to you, Mr. Chairman, and the members of the committee for your courtesy and consideration and intelligent attack of this problem.

Mr. Jarman. Thank you very much, to you and Mr. Gettings, for being with us this morning.

Our next witness is Dr. Harold Visotsky, director of the Department of Mental Health of Illinois, accompanied by Mr. Harry C. Schnibbe, executive director of the National Association of State Mental Health Program Directors, here in Washington.

We are happy to have you gentlemen here with us to make a record on this important subject, and I would be remiss if I did not mention that Dr. Visotsky testified on the original legislation in 1963.

STATEMENT OF DR. HAROLD VISOTSKY, DIRECTOR, DEPARTMENT OF MENTAL HEALTH, STATE OF ILLINOIS; ACCOMPANIED BY HARRY C. SCHNIBBE, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE MENTAL HEALTH PROGRAM DIRECTORS

Dr. Visotsky. Thank you, Mr. Chairman; for the record I am Harold Visotsky, and I am director of the Department of Mental Health in Illinois.

The care and treatment of the mentally retarded is a responsibility of my department in the State of Illinois. We have six residential facilities housing some 10,000 mentally retarded, some six zone centers with inpatient and day treatment programs are being built.

These are Illinois programs for comprehensive health, mental retardation programs. They are not federally financed. They are financed by the State.

We have 34 day centers supported in whole or in part with State money. In addition, we have some 500 patients, applicants for admission, to State facilities who are partially supported in 24-hour private facilities while awaiting admission.

Our Illinois budget for this last beinnium for treatment was approximately $67 million, and we had some $9.5 million for capital construction.

Projected for the next biennium is some $109 million for operations, and some $76 million for capital construction. Fifty-four million dollars of this is added in a bill presented to the members of the legislature for six facilities housing some 2,400 new patients.

The total amount of money in bills now before our Illinois General Assembly for the State mental retardation program is 150 percent more than was appropriated for the current biennium. This indicates how fast we have to move to attempt to make up for our previous years' neglect, but it does not mean we have not made progress in improving services.

For example, in the last 3 years we have added three new State residential facilities for the retarded, approximately some 1,200 beds, and have added over 2,000 patient care employees.

These facilities have been purposely planned to accord with the recommendations and standards set by the American Association for the Mentally Deficient.

What I am saying is essentially this: Up until a short time ago we were running warehouses, and for the first time we are beginning to staff and build, in the sense of program to make these individuals as functional as possible.

In our two schools, Lincoln and Dixon, in Illinois, which are the second and third largest facilities for the mentally retarded in the United States, and we have begun to cut down on the overcrowding in these two facilities in the last few years.

To grapple with problems, unit systems with replication—the unit plan would in effect result in the existence of some 10 or 12 units each being operated as if it were a separate institution for program purposes, but grouped together for administrative and other services.

In other words, we are campusing our facilities.

We are cognizant that the main thrust of mental retardation must be the development of programs outside of State residential institutions. If you only have State residential institutions as the sole intervening source for care, and that is where many of these patients are going to end up, and inappropriately so; for this reason Illinois is requesting more than twice the amount for those now on the waiting list, and we are requesting over a million dollar increase for our support of community operated day care programs.

I am here today representing the National Association of State Mental Health Program Directors. It has responsibility for the care and treatment of the mentally retarded.

In 32 States the members of our association have total administrative responsibility for the treatment of the institutionalized mentally retarded. In these States the members of our association operate 96 institutions and treat annually 140,512 patients.

In 21 other States and territories our members have partial responsibility for the treatment of the institutionalized mentally retarded. Adding it up, you get something like 154,000, which is 82 percent of all institutionalized mentally retarded that are essentially in public institutions.

Last year the States invested over one-half billion dollars in the care and treatment of the mentally retarded and over 100,000 persons are employed to carry out this duty.

However, in spite of the tremendous effort by existing public agencies to care for the mentally retarded we are providing adequate treatment for only a portion of those in need.

We are critically short of both inpatient facilities, outpatient facilities and community facilities such as day care programs and sheltered workshops.

Last year our association surveyed the States and territories to determine the number of applicants awaiting admission for treatment in public residential facilities.

In 49 States and territories responding there were 31,509 persons in our so-called "waiting lists." In most States the duration of wait before admission is about 2 years. In some States it is 5 or 6 years.

And it is a demonstrable fact, Mr. Chairman, that there are two or three times the number of mentally retarded who need help who are not now getting adequate care and are not now on the waiting lists.

I say "so-called" waiting lists because in most States the duration of wait is about 2 years before admission, as I said, and in some States 5 or 6 years.

If we wiped out all waiting lists today and started with a clean slate, by tomorro we would have double the present number of applicants in our State and across the country.

One of the legislators in my State told me, "Doctor, now that we are adding 2,400 beds to our facilities and you have 2,400 patients on the waiting lists, don't you think you have wiped out the waiting list, and we won't see you again soon?" The answer is "No." I think in the next few months we will have 1,600 to 1,800, because the need is so great.

The waiting lists are at 30,000 instead of 90,000 simply because 60,000 families know the futility of applying for help.

Mr. Chairman, I ask permission at this time to submit for the record a copy of the 1966 survey conducted by the National Association of State Mental Health Directors of the number of applicants awaiting admission to State treatment facilities for the mentally retarded, knowing, as I have explained, that these are the people who have indicated they want to come in.

Mr. JARMAN. The committee would be glad to have it.

(The report referred to follows:)

AVAILABILITY OF SERVICES, JUNE 1966

State facilities for the mentally retarded

State and capacity of facilities	Applicants awaiting admission	Duration of wait
Alabama (2,200)	550	2 to 3 years.
Alaska (30)	None. Profoundly or severely retarded are being admitted to contract private facility near Salem, Oreg.	No wait now, but Salem facility near capacity and when filled, waiting list will again build up.
Arizona (1,000)	254 on active waiting list. There are another 61 on the inactive waiting list.	Waiting time varies from less than 1 year to over 3 years, depending upon cottage classification. Except for some urgent cases, the average waiting time for cottages housing "severely" and "profoundly" retarded children is generally over 2 years. The wait for ambulatory, profoundly retarded boys is over 3 years.
Arkansas (550)	745 "profoundly" and "severely" retarded.	3 to 4 years.
California (13,000)	1,000 severely and profoundly retarded. 1,000 not severely or profoundly retarded.	9 months.
Colorado (1,900)	246 children and adults	Wait varies according to urgency of situation.
Connecticut (3,650)	73 on "urgent waiting list." These are mostly profoundly and severely retarded with about 15 percent moderately and mildly retarded range.[1]	Waiting time for profoundly or severely retarded averages out at about 2 years but actual wait is dependent on area of State and timing of request.

See footnotes at end of table, p. 90.

State facilities for the mentally retarded—Continued

State and capacity of facilities	Applicants awaiting admission	Duration of wait
Delaware (575)	17. (Also have 26 referrals on whom information is being collected before they are put on list.)	3 to 6 months in male and female cottages; no pending cases in pediatric wards.
District of Columbia (1,250)		
Florida (4,000)	1,456 includes 45 critical emergency; 292 active urgent; and 1,119 active nonurgent.	Waiting time depends upon classification of applicant's emergency and availability of beds.
Georgia (1,850)	1,821	30-month average for the last 25 admitted but these were all considered emergencies. Average for all cases would probably be 3 to 4 years.
Guam		
Hawaii (800)		
Idaho (725)	None	Temporary care program has eliminated waiting list.
Illinois (13,000)	2,227	2 to 6 years.
Indiana (3,850)	1,478	Wait depends on type of case. Emergencies are admitted immediately; less emergent cases have been on the waiting list as long as 5 years, and sometimes longer.
Iowa (2,000)	No waiting lists maintained	Admissions may be deferred after preadmission evaluation.
Kansas (700)	128 includes 46 boys from ages 2 to 21 and 32 girls from ages 2 to 21.	24 months, approximately, for boys, and 18 months, approximately, for girls.
Kentucky (1,100)	250 as of Apr. 30, 1966	Varies from several days to 2 or 3 years according to mental and physical handicaps. Several days to 1 month for ambulatory cases; several years for profound "crib cases."
Louisiana (2,100)	1,480	Not presently available.
Maine (1,100)	90, approximately	Variable wait, depending on need. For example, 2 to 4 weeks for diagnostic evaluation admission; 2 to 4 years or longer for admission for custodial care of diagnosed dependent retarded.
Maryland (2,800)	156 includes approximately 100 severely and profoundly retarded.	1 week to 2 to 3 years.
Massachusetts (8,700)	903	6 months to 5 years.
Michigan (12,600)	671 includes 463 profoundly retarded and 208 severely retarded.	For the age group 0 to 7 (nursery) the profoundly retarded with a regular status wait about 34 months for admission, and the severely retarded about 27 months. Both profoundly and severely retarded on regular status, 7 years and over, wait approximately 41 months between commitment and admission. Figures for both age groups vary between hospitals and the latter figure also varies somewhat with sex.
Minnesota (5,700)	632 total as of Apr. 30, 1966. This includes 452 profoundly and severely retarded and 180 mildly retarded.[2]	2.9 years average wait.
Mississippi (1,200)	536	3 to 5 years, usually.
Missouri (2,500)	531	Over 1 year. "If a person were added to the waiting list today, there is about a 46 percent probability that the person would be admitted within the ensuing year."
Montana (900)	261	3 years.
Nebraska (2,350)	60 to 75, at present (except for babies under age 1).	Approximately 1 year.
Nevada (150)	None	None.
New Hampshire (1,000)	100, approximately, at present. Number constantly increasing.	6 to 12 months. This period is also increasing.
New Jersey (6,000)	1,213. This includes a total of 745 "severely" and "profoundly" retarded.	At present rate of additions to waiting list, average wait will be 2 to 3 years (until new institution opens in late 1968).
New Mexico (550)	544	An estimated average of 18 months.
New York (24,000)	942 as of Mar. 31, 1966. This includes 91 under age 5 and 851 over.	Varies from 3 weeks up to 2 years, depending upon location.
North Carolina (4,400)	663 as of Apr. 30, 1966.	2 years for severe, nonambulatory. 3 to 6 months for moderately retarded and no wait for mildly retarded.

See footnotes at end of table, p. 90.

State facilities for the mentally retarded—Continued

State and capacity of facilities	Applicants awaiting admission	Duration of wait
North Dakota (1,200)	85 to 90. Includes approximately 50 profoundly and severely retarded.	1 to 2 years, approximately. This is expecteed to be reduced somewhat in in about 2 years.
Ohio (10,000)	Since Ohio operates on a county quota system, no accurate waiting list is available at the institutions. However, it is known that there are at least 500 nonambulatory patients awaiting admission. At least 300 ambulatory severely and profoundly retarded are known.	2 to 5 years for nonambulatory. 1 to 2 years for ambulatory severely and profoundly retarded.
Oklahoma (2,300)		
Oregon (2,600)	150	Wait varies considerably with the age and specific problems of the individual retarded, as State is able to accommodate some groups much more readily than others. The longest anyone has been on the active waiting list is approximately 2½ years.
Pennsylvania (11,400)	3,641 as of Feb. 28, 1966. Includes an estimated 1,014 severely retarded and an estimated 350 profoundly retarded.	4.8 years for profoundly retarded; 2.8 years for severely retarded.
Puerto Rico (175)	200	Duration of wait is very long.
Rhode Island (1,000)	No waiting lists maintained	[3].
South Carolina (2,850)	1,065	Approximately 3 years for nonambulatory profoundly and severely retarded; 1 to 2 years for trainable moderately or severely retarded; no wait to 6 months for educable retarded. (Exceptions to the waiting list are made for emergency cases of retarded dependents of military).
South Dakota (1,300)	70, approximately	Average is approximately 2 years, but varies according to sex, age, level of intellectual functioning and other factors. "If a person were added to the waiting list today, he might be admitted tomorrow or he might have to wait for more than 2 years."
Tennessee (2,100)	2,000, includes 700 critical and 1,300 noncritical.	2 years for critical.
Texas (10,000)	1,100	Depends on type. Generally 18 months.
Utah (850)	300 to 350	2 to 3 years.
Vermont (650)	57	1 year for ages 2–6; 6 months for ages 6–21; 1 year for those over age 21.
Virginia (3,500)	228 on active list as of Apr. 30, 1966.	3 to 6 months for urgent cases. Longer for less urgent cases.
Virgin Islands		
Washington (4,000)	1,261 as of Apr. 30, 1966	Waiting time estimated to be about 2 years, based on waiting times for admissions in 1964 and 1965.
West Virginia (550)	117	An average wait of 3 years in most categories.
Wisconsin (3,700)	238 as of Mar. 31, 1966. This includes 2 emergent; 40 urgent; 65 desirable; 118 indefinite; 13 miscellaneous.	No average wait, as this is determined by the degree and nature of the handicap. Emergent classifications have very little wait while others have varying durations depending on a range of variables.
Wyoming (700)		
Total	31,509	

[1] Connecticut: Prerequisites for the urgent waiting list include willingness of the family to accept placement immediately when offered and the presence of detrimental effects on the family caused by continued maintenance of the retarded member at home. A sizeable number of families have indicated an interest in residential care at some future and not-to-be-defined date, but these are not shown on the present urgent waiting list.

[2] Minnesota: There is careful evaluation to determine whether the problem presented is primarily one of mental retardation or whether it is one of social maladaptation with mental retardation as an associated symptom. Treatment and training plans would utilize a variety of resources appropriate to the needs of the individual such as more intensive family treatment, use of homemaker services, foster care, private residential care, or a State residential facility.

[3] Rhode Island: All referrals for service or admission are processed by virtue of applications being completed, summaries collected, medical and psychological testing administered. At this point a diagnostic conference is held and admission or community sustaining services is recommended. If admission is denied, social service staff are asked to try and sustain the patient in the community by use of whatever service may be available. Periodic review is made when indicated of cases on Community Sustaining Services and new factors are considered and a decision made to admit or not admit. As to numbers, there are currently 110 active referrals on file. 50 of these have been processed and denied admission. The remaining 60 are either in process, or retardates located in other State facilities, such as Child Welfare Services' foster homes, State Institute of Mental Health and Zambarano Hospital. Approximate numbers: Child Welfare Services (foster homes), 4; Institute of Mental Health, 16; Zambarano Hospital, 20; own home, 20.

Dr. VISOTSKY. Thank you, Mr. Chairman.

All the foregoing is by way of illustrating to you some of the magnitude of the problem.

It is by way of emphasizing why we are here before you today asking for further assistance from the Federal Government in developing programs to meet, or help meet, the staggering national needs in the treatment of the mentally retarded.

I come before you today to tell your committee, first of all, that our association supports the proposals, as embodied in several bills before your committee, to extend and expand the present Federal matching programs providing aid in the treatment of mental retardation.

We endorse without reservation H.R. 5110, a bill introduced by Congressman Waldie, of California, and referred to your committee.

We give limited endorsement to H.R. 6430, sponsored by Mr. Staggers, and H.R. 7688 sponsored by Mr. Carey, suggesting that these bills do not fully meet the needs of progressive mental retardation treatment programs in the States. Therefore, we respectfully recommend several changes in those bills.

Mr. JARMAN. May I ask, are the changes you recommend, are they in line with the provisions of H.R. 5110?

Dr. VISOTSKY. Yes, they are. I will discuss the variations and why we think 5,110 fully meets our recommendations.

I will discuss the changes we propose in H.R. 6430, which is the bill endorsed by the Department of Health, Education, and Welfare.

First, we favor the Federal Government providing assistance for a range of services for the mentally retarded—rather than merely support for one component of service, for example, "staffing." Significant costs other than "personnel" are involved in providing high, as Dr. Boggs explained, quality care for retarded persons. "Transportation," for example, may represent 25 percent of the cost of operating an effective day care program for the mentally retarded.

When I reviewed a program just 3 weeks ago, I found it was failing. It was failing with good people, and it was failing because they did not have contractual funds for transportation, and out of my contingency funds I provided some $7,000 for a bus transportation contract, and that program I know will begin to succeed.

H.R. 5110 focuses on providing assistance to a total service for the mentally retarded. H.R. 6430 provides assistance only toward employment of professional and technical personnel.

We support the provisions of H.R. 5110.

Second, we favor flexibility in the Federal matching program for services to the mentally retarded in community facilities.

A sharply declining matching formula as proposed in H.R. 6430 (similar to the "staffing" features of the Community Mental Health Centers Act) will not work in facilities for the mentally retarded.

In developing the program for the mentally ill it was anticipated that over a 5-year period third-party payments—Blue Cross, medical insurance and title 19 programs—would increase the income to the centers as Federal assistance declined.

This is not likely to occur in the case of mentally retarded persons being cared for and trained in community facilities.

And one cannot expect the United Givers Fund to step in and readily absorb what I would call the steep escalation in non-Federal support that will be created by the provisions of H.R. 6430.

The variety of kinds of service needed and the duration of individual need in the case of the care and training of the mentally retarded require a Federal matching system different from that provided in Public Law 89–105, staffing of community mental health centers.

Third, we support the concept of Federal assistance for mental retardation programs that are now in existence as well as new types of service.

Gentlemen, from my point of view we have a bunch of small demonstration projects that have demonstrated their usefulness, and they remain small and they remain ineffective; and in returning some good on our risks it is often more economical and feasible to expand or improve an existing service than to initiate a brand new one.

Fourth, we endorse the feature in H.R. 5110 that requires the Secretary of HEW to give preferential treatment, in making grants, to new or expanded services for the mentally retarded that are funded in some part by State or local government.

The reason for this is most logical. The States and counties, municipalities must be encouraged to enlarge their interest in providing high quality public care and training programs for the mentally retarded.

The nature of mental retardation demands long-term financial stability in the continuum of care needed for retarded individuals. Inevitably this involves the use of public funds. The financing which faces you faces States, and States try and pass on the load to municipalities; and our strategy in Illinois is to set up the partnership in which the need is so great that we must multiply finance these programs, and I might also say that we have a millage tax in Illinois which we passed 2 years ago which allows communities to tax themselves 1 mill per thousand.

There are 14 communities which have passed referendums to tax themselves for mental health and mental retardation programs.

One program, in Decatur, which was run by a private group, has now gone public. Now we can step in and begin to support them at a State level and hopefully add an immediate level in a true partnership. They cannot be dependent solely on a campaign once a year hoping to go over the mark.

And fifth, rather than distributing the moneys allocated under this proposed program on the basis of a "formula," it is our recommendation that the funds be distributed on a "project" grant basis.

The normal "formula" for distribution of Federal grant funds is "per capita income," "population," "need for services," and this is the system proposed in the administration bill, H.R. 6430.

We do not endorse this system for a program of support for "initiating services" in community mental retardation facilities.

Distributing Federal funds on a formula basis in a brandnew program that has a relatively small amount of appropriations is generally inefficient and inequitable.

If the first year's money under H.R. 6430 were divided by the number of States, the amount going to each State would be $132,000. This indicates what a small amount of money we are talking about.

Now, we are not suggesting that the appropriation figure be changed; only that the method of distributing it be changed.

It should be distributed to projects within the States, based on the tatus of readiness of the projects and the critical nature of their need.

In Illinois, we have divided the State into some 72 areas, by 11 variables, the economic status, the ability to move, that is based on professional resources, are all graded on a priority basis; and on this table we are able to really fund organizations on the basis of not only need, but the readiness to move.

These are new programs in the States and they are in varying degrees of progress. Some States have several projects in urgent need; other States are not as ready. To distribute the funds on the basis of a "formula" is wasteful.

I think it wasteful, because everyone will take it, and I think the programs will not show the success that we are trying to initiate.

Sixth, H.R. 6430 calls for $7 million for the fiscal year ending in June 1968. We support this.

Knowing the desire of the Congress to have specific authorizations for the subsequent years of the program we therefore recommend $15 million for fiscal 1969, $20 million for 1970, and $30 million for 1971.

Our association supports the provisions of H.R. 6430 that would extend part C of Public Law 88–164, "Grants for Construction of Community Facilities for the Mentally Retarded," for another 4 years—that is, 4 years after fiscal year 1968.

We also consider of highest importance the extension of part B of Public Law 88–164, "Construction of University-Affiliated Facilities for the Mentally Retarded." H.R. 6430 would extend this program through fiscal 1972, and we support this.

I might also say that before I became a director of the department of mental health I was a university professor. My biggest difficulty was getting the members of the university interested in the community. When I went to medical school, the advice was "advise the parent to place their children." I think this is terrible. I think the linkage between the universities and the community programs is what we must begin to design.

Mr. Chairman, the plight of the mentally retarded in this country is well known to you and the members of this committee. It was this committee that, in conjunction with the Senate Labor Committee, originated the first major construction program for facilities for the mentally retarded.

I don't think I need to document the great need for a substantial, ongoing partnership between the Federal Government, State and local governments and private nonprofit organizations in the development of progressive care and training programs for the mentally retarded.

Our principal appeal today is not to persuade you that there is a need for more "bricks and mortar" for construction of facilities for the mentally retarded.

We think you are well aware of the need for extension of the construction program.

We come before you today to ask for help in developing initial services to the mentally retarded that embrace more than simply personnel. And we ask that this program of Federal support for "initial services" be designed so that it is quickly effective, cleanly efficient and totally equitable.

We think that these objectives can best be attained by the substitution of H.R. 5110 for part D of H.R. 6430, and we so recommend this.

Thank you, Mr. Chairman.

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Mr. JARMAN. Thank you.

Does Mr. Schnibbe have any additional statement or questions?

Mr. SCHNIBBE. No, Mr. Chairman.

Mr. JARMAN. One thing that I think would be helpful to us, and I am glad you approached it in the manner you did, is the comparison between bills that have been introduced, the position that you take and recommendations that you make.

Mr. Rogers?

Mr. ROGERS. I remember very well your testimony on mental health and the Community Mental Health bill, which was most helpful to the committee, particularly with the experience you had in Chicago. As I recall your testimony, your centers there that had been the basis of experience that we can go on.

Now, in your operation in Illinois, have you received any of the Federal moneys that were formerly approved for construction of these centers for the mentally retarded?

Dr. VISOTSKY. Yes, we have, somewhwere around $1.3 million for centers, and we have used them all.

We have a bill before our legislature now to match the Federal effort by putting in 30 percent of the cost.

Mr. ROGERS. For the State to do this?

Dr. VISOTSKY. Yes, so that it would truly reflect the partnership.

Mr. ROGERS. Then would the local community put in a contribution?

Dr. VISOTSKY. Yes, 31 percent, or we could put this on a swinging scale. If they can't do it——

Mr. ROGERS. I think some areas have not tied in their State at all, but have simply left it as a local effort, and I think the trend you are starting might be looked at by other States.

I think this might be an encouraging sign.

Dr. VISOTSKY. Let me say, Mr. Rogers, we felt the State ought not to be the applicant for Federal moneys to build State-run facilities. We thought this ought to be a local effort.

That State, that is, Illinois, under my direction, has not applied for any of these funds. I will not let them do that. I think it is the responsibility of our general assembly to provide their share and go ahead with the program projected during these past 6 years.

On the other hand, we are talking about partnerships, and I am asking communities to have a referendum on the millage tax for continued maintenance, and so in a sense I am asking our legislature to put their money where their mouth is.

If we are talking about partnership, then we ought to put in at least 30 percent to match the Federal share, and come to the communities and say, "We know 61 percent is just too much for you to manage; would you put in what we think is a reasonable amount?"

Mr. ROGERS. Good. What about your research centers for mental research, the centers in Illinois?

Dr. VISOTSKY. University research centers?

Mr. ROGERS. Yes.

Dr. VISOTSKY. There is one at the University of Illinois. It wasn't a construction grant. It got an equipment grant. Most of the funds, I think, came from the Kennedy Foundation.

Mr. ROGERS. What about any of your university affiliates for mental retardation?

Dr. VISOTSKY. Within our department, Mr. Rogers, we run a training institution. It is funded by our mental health fund, which is a research and training fund.

If you remember, the last time I explained that the payments of patient or third-party payers go into a special research and development fund.

Now, that pediatric institute is related directly to the University of Illinois Department of Pediatrics, and other research centers. They have common staffing patterns, and we are now writing a contract which will allow us to relate directly at both the university level as well as the community research and development level.

Mr. ROGERS. When a local community would want to establish one of these retardation centers, should they provide all of the services, or should it just be one service, or what?

Dr. VISOTSKY. One of the problems in providing what I would call laundry list services is that it overwhelms communities. We want to plan, and as you know we divide our State into eight zones, and each zone has a mental retardation advisory committee, and they say, "What do we need to provide, total facilities for the mentally retarded in this area?" An applicant must be able to integrate his program into the total plan for that zone.

Now, he may buy one or two areas of service, or he may be only buying one—providing one area of service, but if he does that, I think it is worthy of support, because to try and tie them to a contract which is so comprehensive that it overwhelms them, I think is unreasonable in initiating services.

Mr. ROGERS. Thank you very much.

Thank you, Mr. Chairman.

Mr. JARMAN. Mr. Brown?

Mr. BROWN. Doctor, I would like to pursue this question of how we establish the priorities on which these grants should be made.

You indicated that you have established priorities in Illinois. These, I gather, are not necessarily on the basis of the development of the community in its care facilities for mentally retarded——

Dr. VISOTSKY. Yes, that is one of the variables, Mr. Brown.

Mr. BROWN. But only one?

Dr. VISOTSKY. Yes, it is one of many, they are correlated in terms of other ranking——

Mr. BROWN. In other words, you do not necessarily give priority to an area which has done nothing in this area?

Dr. VISOTSKY. That is right, we don't give priority to somebody who has done nothing. We do give priority to those who have nothing but have an intent to move ahead and can't provide the resources.

For example, there are many communities that have parents groups, but have nothing for their children. They support our program, and they go out to some of the hospitals and they want to start something in some areas.

Mr. BROWN. This is the point I am making. Do you give preference to those, or do you give preference to somebody who has established a project and wants to go ahead?

Dr. VISOTSKY. We might give some preference to a community that has something, that has good resources, and are in an area of great economic need, and make a population center in which the number of retarded, based solely on population, may be greater than

in other areas, so those are some of the variables that we take into consideration in ranking on the basis of priority.

At this time, I might say that the money is so short, and the need is so great, that for the most part, except that it is an outrageously "have" community, we have taken most comers who want to get involved in this business.

Mr. BROWN. In other words, you spread your money out a little here and a little there so that you can stimulate the local areas?

Dr. VISOTSKY. It is seed money, not feed money.

Mr. BROWN. Right. That cuts to my basic question, and that is how Congress should provide these funds that are, as has been pointed out by you and the preceding witness, limited at this point.

Should they be scattered around a little here and a little there as seed money; should they be given to those who have done nothing so far to get them started; should they be given to a community that has a fairly good program and has proved their ability to operate a program and wants to elaborate on that ability?

This seems to me a very difficult administrative decision.

Dr. VISOTSKY. It is, and so it is for us. Don't misunderstand me. I think when we begin to spread the money around we literally scatter it the way seed are scattered.

I am not a farmer—I am a city boy. I know you need 20 times as much seed, and you throw 20 times as much around to get it to grow.

That is not a good way to spend money. We try to select the programs with the highest return over effort, and give them the money.

Mr. BROWN. My point is, who should make that decision? Should it be made close to the local level, by the Federal administrator, should it be made by the Congress in trying to establish a formula?

I gather that your suggestion on page 5 is that we not try to spell out too specifically in the legislation what the formula for distribution of these funds should be.

Dr. VISOTSKY. If you will take my bias, in consideration, I would say it should be taken by the professionals at the local level because they know their own resources well. One of the reasons we divide the State into eight regions is that the plan in that area should be in line with the needs of the people in that area.

If it comes down by a formula grant, it is equality, but it is equality that diminishes our effort rather than encourages it.

Mr. BROWN. How local?

Dr. VISOTSKY. I would say at least at the State level, because we do have State planning grants that are provided in previous years, and there have been plans provided for those States.

Mr. BROWN. Should we attempt to equalize among the States at some level, either in the Congress or the Federal administrative level?

Dr. VISOTSKY. I would say no, because again what is true at the State level is also true nationally. Some States are ready to move, and I think this ought to be the responsibility of your Secretary of Health, Education, and Welfare. He is going to have to have the guts to make those discriminations and support those programs that are moving.

Mr. BROWN. That gets into my next question, and that is what if the Secretary of Health, Education, and Welfare doesn't make the same sort of discriminating judgments you make at the local level?

In other words, what if he has the feeling that these ought to be administered on the basis of the community which has done very little in order to get them stimulated into the activity, rather than to give it to a program which has progressed to some degree and wants to expand into another area, such as preschool or adult retarded?

Dr. VISOTSKY. Mr. Brown, if he has a good evaluation program, he will know that spreading it around will not pay off.

Mr. BROWN. I am not suggesting that. I am suggesting that his method of evaluation may vary radically from yours in Illinois. He may feel that to get a program started is much more worthwhile than to assist an existing program in the elaboration of the services it provides.

Dr. VISOTSKY. I can only speak for this Secretary, because, as you may know, I was on his advisory committee for trying to evaluate the health programs. I do not think he would disagree with the key professionals in this field as to where the best use of this limited amount of funds should be extended.

Mr. ROGERS. Would the gentleman yield?

Mr. BROWN. Yes.

Mr. ROGERS. Does it not basically go back to your State plan? The Secretary is not going to come in after you have set your state plan and tell you to change that, is he?

It is predicated on the basis that it is properly planned. They come up with a State plan based on local needs, and how it is integrated within the State and what services should be built. It is the needs within the State and the capability, and this is what the State plan is to project, and then the Secretary goes along with that, once his plan is accepted, as I understand it.

Dr. VISOTSKY. That is correct, Mr. Rogers, and I thank you for it, because that is what was asked of us when we were given money to set up a State plan.

Secondly, one of the problems of a State plan, unless you implement it in accordance with the priorities that—in that State plan, it is on the shelf.

Mr. BROWN. And there are different views, or priorities, in varying States.

Dr. VISOTSKY. Yes.

Mr. BROWN. But the Secretary generally has, and you feel he should recognize the State viewpoint of its own priorities rather than an overall view of priorities, even though they may vary within the States?

Dr. VISOTSKY. I think that is correct, and where there are major differences, where a State takes a plan and runs with it, which is not consistent with good professional judgment, they will stand out.

I think that will probably have to be negotiated locally by citizens groups and professional groups in the State. That is how you get people involved.

Mr. BROWN. Thank you.

Mr. JARMAN. Mr. Satterfield?

Mr. SATTERFIELD. No questions, Mr. Chairman.

Mr. JARMAN. Thank you very much, gentlemen, for your contribution to our hearing.

Dr. VISOTSKY. Thank you, sir.

Mr. JARMAN. This concludes our list of witnesses on these bills, and we want to express our appreciation to all of you for being with us.

The subcommittee will now stand adjourned.

(The following material was submitted for the record:)

STATEMENT OF THE AMERICAN OPTOMETRIC ASSOCIATION PRESENTED BY MORTON DAVIS, O.D.

Mr. Chairman and Members of the Committee: I appreciate the opportunity to make this statement on behalf of the American Optometric Association. I am Dr. Morton Davis, an optometrist, practicing in Bethesda, Maryland.

Because of the correlation between vision problems and mental ability, our Association is concerned with two bills being considered by this Committee—H.R. 6430 and H.R. 7688. These bills are similar except H.R. 7688 contains two sections not contained in H.R. 6430:

1. Section V which relates to enforcement of State Standards of Operation, and
2. Section VI which authorizes additional sums for the education of handicapped children.

Our Association strongly endorses the additional authorization for the education of handicapped children. Few people realize the direct relation between vision and mental development. Statistics demonstrate that vision and mental development go hand-in-hand. Many cases on record show that as better vision is developed, mental development keeps pace with it.

In my optometric practice I deal with vision problems of children with learning disabilities. If a vision problem is exceedingly severe, the child may appear mentally retarded as a result of the vision problem. Other children with vision problems are slow learners and still others can function although their school work usually becomes a chore.

A paper given at the 1965 American Public Health Association meeting estimated that there are 250,000 mentally retarded children in our country who also have significant uncorrected vision defects. The estimate was based on a program for 6,158 mentally retarded children conducted by the Detroit Health Department.

My practice during the past 16 years has enabled me to assist many children in improving their visual capabilities. I will mention a particular case, that of a five year old child with a mental age of 2.5. After her first year of visual training, her mental age improved to 4.9 years. She was able to change her mental classification from institutional to educable.

Much of the present research in retardation is toward sensory motor development which relates directly to optometric training and practice. Caring for adults who have experienced marked declines in perception, while important, is not as difficult to control as caring for a child who has always been retarded by a serious vision problem.

While we have made progress, we still have much to learn concerning methods and procedures to be used. The first problem is to discover and evaluate the child's visual capabilities, then correct them by means of lenses, visual training or both. Determination of the proper lens for a mentally retarded child is very difficult and visual training presents even more complicated problems. To succeed takes knowledge and patience on the part of the optometric practitioner and the other members of the professional team working with the child.

Our association has three committees which deal with this area: The Committee on Visual Problems of Children and Youth; the Committee on Orthoptics and Visual Training; and the Committee on Aid to the Partially Sighted.

AOA publishes a monthly journal which contains articles of interest to our profession. Through the years the *Journal* has carried various articles which deal directly with vision and the mentally retarded child.

The February 1963 issue was dedicated entirely to the subject. One article in this issue, "A Discussion of Physical and Perceptual Environment in Visual Training of Mentally Retarded Children," was written by Dr. Harold L. Friedenberg of Richmond, Virginia, Chairman of AOA's Committee on Visual Problems of Children and Youth. Another paper "Vision Care of the Mentally Retarded Child: A Preliminary Report," was prepared by Dr. Harold N. Friedman who serves as consultant optometrist, Clinic for Mentally Retarded Children, Flower Fifth Avenue Hospital, New York City. Dr. Elwood H. Kolb,

faculty member of the Pennsylvania College of Optometry and Director, Eye Clinic, Lehigh County Chapter, Pennsylvania Association for Retarded Children, Inc., authored an article titled, "The Eye Clinic Approach to the Retarded."

A fourth paper, "Visual Perceptual Training and the Retarded School Achiever," was written by Dr. James Tramonti, an optometrist practicing in Providence, R.I. "The Philosophy of Developmental Vision," was the title of an article written by Dr. Jerome Rosner. Dr. Rosner is an optometrist who serves as a member of the Advisory Council for Mentally Disturbed Children, United Mental Health Service, Allegheny County, Pennsylvania.

The Optometric Extension Program, is a non-profit educational corporation dedicated to postgraduate education of optometrists. When OEP gave its first formal course in 1955 the subject was "Vision and the Retarded Child."

At the 1960 White House Conference on Children and Youth, AOA submitted as part of its report an appendix, "Optometric Visual Care for the Brain Injured Child." The appendix was written by Dr. G. N. Getman, an optometrist who had been associated with the respected, late Dr. Arnold Gesell of the Yale Institute of Child Development. Dr. Getman is continuing his research on vision and retardation with the Pathway School in Pennsylvania.

A recent issue of the U.S. Children's Bureau journal, *Children*, contained some interesting facts on vision and mental retardation. A study conducted by the Michigan State Health Department showed that ten of fourteen severely retarded children had serious vision problems. In a group of children not severely retarded, the incidence of vision problems was closer to normal, one or three.

Another issue of *Children* carried an article title, "The Effects of Blindness on Children's Development," by Jerome Cohen. He said that 50% of the totally blind children studied were mentally retarded, but only 33% of the partially sighted children were mentally retarded.

Eighty percent of everything a child needs to learn enters his nervous system through the sense of vision. Any disorder in his visual system has an effect on learning, and learning ability has its effect on development of vision—so it is a two way street.

An interesting article relating to learning ability and visual development, "The Boy Who Found the Sun," by Jhan and June Robbins, appeared in the December 1966 issue of *Redbook* magazine. Joseph Michael Perez, Jr., at age five years and three months had an I.Q. of 44 and went around as though blind, never avoiding hazards. He also had a spastic quadriplegia. Both his parents were blind.

An understanding teacher placed Joey in a class with mentally normal children. Some of the children, discovering that Joe could see, encouraged him to lift his head and take a look. Joe had not learned to use his eyes. When this was discovered, Joey began to see, understand and therefore learn. Today he is considered a normal child with physical defects.

Paula, a little girl from our own office, is in a special school for learning disabilities. She had one eye which turned outward and she could not converge her eyes to look at anything close to her. Visual training was used to help her keep her eyes straight. She has obtained cosmetic improvement and her teacher says Paula is now beginning to learn to read.

Another of our patients, Robin, had an eye which turned in. He had surgery and afterwards was unable to turn his eyes in even while looking at near objects. Robin's mother, a Montessori teacher, has worked with children with learning problems and is well qulified to observe children. She told us that all types of materials had been available to Robin and for three years he had participated in a program designed to encourage development of pre-reading skills—coloring, painting, etc. Robin responded to visual training beautifully. He began doing all the things he had never done before; he could concentrate on objects close to him—especially important as most school learning situations are near point tasks.

One of the first cases of a brain damaged child I ever handled professionally was Ricky. He had minimal brain damage and was continually on barbituates from age two years. He also had a vision problem. His other problems were so severe that no one paid attention to his vision. Ricky responded marvelously to visual training. Some years later I was in Miami Beach, Fla. While there I received a phone call from Ricky who asked if he could drop by and say hello to my wife and me. I would never have recognized the handsome boy who came to the door. Then a sophomore at the University of Miami, Ricky gave us a copy of his high school graduation picture—that photo means more to me than any other award I have ever received.

Over the years we have also had many frustrations. Much remains to be learned about the relationships between vision and learning. There is a great need for research and development in this field. For every retarded child who has been helped, we can point to many who have not been helped. These children are being condemned to a life of dependency and frustration.

Members of the optometric profession have organized and support the Optometric Center of New York which provides vision care for patients of all ages (regardless of ability to pay) and conducts research in the field of vision including developmental vision and mental retardation. Its record of achievement has been commended by both municipal and state authorities.

We have also established and maintain the Optometric Center here in Washington where we care for patients referred by various charitable and religious organizations operating in the Nation's Capital. Similar work is being conducted in many metropolitan areas throughout the country. Members of the optometric profession, like others in the health care field, are dedicated to service of our fellow man. For this reason we have a genuine interest in problems of mental retardation. We believe that passage of this legislation is in the public interest and we are confident that members of the optometric profession are in a position to assist in carrying out the programs once established.

We understand that Federal funds will be used for staffing mental retardation centers and clinics. We hope that optometrists will be employed in serving the mentally retarded thus assuring comprehensive care for these unfortunate individuals who need our assistance so much.

Thank you for the opportunity to present our testimony.

STATEMENT OF DR. ROBERT E. COOKE

As Professor of Pediatrics at the Johns Hopkins University School of Medicine, and Pediatrician-in-Chief of The Johns Hopkins Hospital; as a member of John F. Kennedy's President's Panel on Mental Retardation; as a present member of Lyndon B. Johnson's President's Committee on Mental Retardation, I have had the opportunity to plan and build the first University Affiliated Clinical Facility for the Mentally Retarded. For the past three years, planning and programming have gone on week after week to develop a new model for universities—a clinical facility concerned with the handicapped in which pediatricians, psychiatrists, orthopedists, physical therapists and others join hands for the purpose of training not only young men from their own disciplines, but also those of every other discipline.

I have personally witnessed the transformation which has occurred in our own great school, Johns Hopkins, where care of the seriously and acutely ill has dominated the thinking of staff and a majority of time of the medical curriculum. This transformation toward concern in research, in teaching, and in service for the retarded and for the handicapped has come about through the planning and efforts toward the University Affiliated Clinical Facility at Johns Hopkins. Our plastic surgeons are now planning operative procedures to improve the appearance of mongoloid children. Our orthopedists are considering ways of correcting the dislocated hips of the spastic retarded. Special educators work with psychologists and pediatricians to find ways of optimizing the performance of the hyperactive retarded by conditioning procedures, novel systems of rewards and drugs.

Nursing educators are developing new curricula for the training of student nurses, graduate nurses, and even Ph.D's in the care of the mentally retarded. Social workers and physical therapists have new teaching programs as well. Extensive planning is even going into courses for parents so that they may be used as the major training resource for these children in their own homes. To this end, our John F. Kennedy Center for Habilitation of the Mentally and Physically Handicapped Child has three parent suites where mother and father and handicapped child may learn together under staff supervision. Similar planning, similar construction is going on in over a dozen centers in various major universities, in a dozen states. But why should only these states and these universities have such opportunities? Why should the retarded of the other thirty-eight states not have the same opportunities to become useful, self-supporting citizens?

I would hope that every major university center that is qualified would have such an opportunity over the next decade.

If government funds are to be wisely used for projects as complex as the University Affiliated Facilities for the Mentally Retarded, planning grants

should be permitted out of the construction authorization, and I would hope the present bill would be so amended.

The Kennedy Foundation made planning grants of $20,000 each to fifteen universities for University Affiliated Clinical Facilities. Twelve have gone on to develop superior plans and programing. The other three used the funds to explore the present feasibility of such undertakings and wisely discovered that they were not yet prepared to take on such a major multi-disciplinary activity. Significant federal and private money was saved by such planning grants.

In conclusion, I would strongly urge that the program represents the major opportunity for the retarded to be helped in the country. The lack of trained personnel in every discipline, in every agency, in every institution, threatens the quality of all services to the mentally retarded regardless of the quantity of funds for care. The University Affiliated Clinical Facilities must be expanded to all regions of the nation to solve the manpower crisis in this field that prevents the application of new research findings in medicine and education to the retarded child and adult.

AMERICAN MEDICAL ASSOCIATION,
Chicago, Ill., May 1, 1967.

Hon. JOHN JARMAN,
Chairman, Subcommittee on Public Health and Welfare,
Committee on Interstate and Foreign Commerce,
House of Representatives, Washington, D.C.

DEAR CONGRESSMAN JARMAN: On behalf of the American Medical Association, I would like to take this opportunity to submit for your consideration, Medicine's views on H.R. 6430 which would amend and expand the Mental Retardation Facilities Construction Act by extending the project grants for the construction of public and nonprofit facilities for the mentally retarded, and by adding a new part whereby the Secretary of Health, Education and Welfare could make grants to help defray the cost of initial staffing of such facilities.

The American Medical Association is on record, in its previous testimony before this Committee, as supporting the appropriate extension of facilities and services for mental health and the combatting of mental retardation on the local level through the implementation of local and state programs. The Association recognizes the vast dimensions of the medical, educational and social problems inherent in mental retardation and has stated that care facilities for these individuals must be integrated into every community's mental health program.

The extent to which the problem of mental retardation can be ameliorated in future years depends largely upon continued research. Although some breakthroughs have been effected such as the prevention of some types of mental retardation as a result of our increased knowledge of body metabolism, there are still gaps in research, personnel and financing which must be overcome. While the ultimate answer to the problem of mental retardation is prevention, we recognize that in the meantime, mentally retarded individuals must be cared for and must be educated and trained to the limit of their capabilities.

In this regard, the AMA supports efforts to provide higher standards of care for the institutionalized retarded, special educational programs, day care centers within the community, counseling services for the parents of retarded children, and efforts to create job opportunities for retarded adults. For these programs to be effective, the nation needs additional facilities and an increase in properly qualified personnel. We therefore are pleased to submit for the record our continued support of the expansion, extension and improvement of facilities and services through construction, training and research grants. We would urge that the Committee favorably act upon these provisions of H.R. 6430.

The bill, however, also amends the present Act to authorize grants for meeting a portion of the cost of compensating professional and technical personnel during the initial operation of the facility. Although such federal financial assistance during the early years might enable a mental retardation facility to undertake a more comprehensive program than it might otherwise attempt, it can be demonstrated that once reliance is placed on a federal subsidy for staffing, the role of the federal government as a provider of operating funds will not easily be ended. Once a facility has been constructed, the community can and should assume the responsibility for its operation, including the costs of staffing.

In conclusion, let me again state Medicine's support of the construction and training provisions of the bill before you, and I urge their adoption. Thank you

for this opportunity granted to the Association to comment upon this important legislation affecting the health and welfare of the more than five million Americans who are mentally retarded.

Sincerely,

F. J. L. Blasingame, M.D.,
Executive Vice President.

The American Public Health Association, Inc.,
New York, N.Y., April 20, 1967.

Hon. Harley O. Staggers,
Chairman, House Committee on Interstate and Foreign Commerce,
Washington, D.C.

Dear Mr. Chairman: The American Public Health Association is privileged to support the principles and objectives included in H.R. 6430, which you have introduced and which would amend the Public Health Service Act relating to mental retardation programs. The continuation of the provisions of the Mental Retardation Facilities Act of 1963 and an extension to provide assistance for staffing needs on a temporary basis is vital to the fight against mental retardation.

The Governing Council of the APHA adopted the following resolution in 1964: "The development of community based services for the mentally ill and mentally retarded has been stimulated by state assistance, state planning bodies, and the recently available Federal funds for construction of community mental health centers and mental retardation facilities. This trend should enhance the quality of mental health and mental retardation services by overcoming their traditional isolation. Incorporation into the main stream of medical, hospital and related health services in the community will bring to the mentally ill and mentally retarded patients the benefit of the full range of modern health services. To secure maximum benefit from this development, it will be necessary to construct facilities and plan services so that they will be truly integrated with the rest of the community health services."

The population of mentally retarded children is increasing in size due to the larger population, and also because advances in other scientific areas is saving the lives of otherwise doomed children who are severely handicapped at birth. We can no longer be content with support of the individual research scientist. The magnitude of the problem of retardation and the range of related research efforts that it requires, demand establishment of research centers so that maximum benefit may be secured by the interplay of the biological and social sciences.

Attracting outside personnel to established mental retardation centers is vital to the changing of these centers from mere storage houses to centers of treatment and rehabilitation. It cannot remain permissible for mentally retarded children and adults to be cared for under programs by no means appropriate for the mentally retarded. The Act of 1963 passed by Congress recognized this fact and its provisions must be extended.

Perhaps the most striking characteristic of mental retardation is the myriad forms it assumes and the corresponding number of its causes. As stated by Dr. Robert E. Cooke before your Committee in March of 1963, the number of treatable cases of mental retardation represents an almost unbelieveably small percentage of those afflicted—in fact, only about 1%. Even when diagnosing the causes of the retardation, the majority of cases are labeled "idiopathic" or of unknown cause. Those causes, which are identified, range over a spectrum, including such widely divergent factors as genetic abnormalities, dietary deficiencies and side effects of other diseases. Ironically, the ignorance evidenced in our treatment (or lack of same) of mental retardation can be attributed to retardation of another sort—that of scientific investigation.

An attempt to deal with these lacks was made when the Congress passed the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963. This was a good start, but only a start. More effort is needed if effective measures are to be taken against this crippling disease.

We are especially anxious that the section of H.R. 6430 providing financial support for a core clinical staff be adopted. Hospitals and universities have no source of support of such personnel at the present time and neither the Public Health Service nor the Children's Bureau is authorized to support such service functions except on a demonstration basis. Support of centers for research on mental retardation and related aspects of human development through Title I of the Mental Retardation Facilities Construction Act of 1963 provided in part the physical facilities needed to develop a nationwide research undertaking. If these physical facilities are to be staffed by scientists dedicated to the study and

treatment of mental retardation, operational funds must be provided to avoid having these centers represent simply a kind of apartment house sheltering old programs rather than leading to aggressive new research.

Your consideration of our opinions will be much appreciated. Please include this communication in the record of hearings on H.R. 6430.

Sincerely yours,

BERWYN F. MATTISON, M.D.,
Executive Director.

AMERICAN NURSES' ASSOCIATION, INC.,
New York, N.Y., May 1, 1967.

Hon. HARLEY O. STAGGERS,
Chairman, Committee on Interstate and Foreign Commerce,
House Office Building, Washington, D.C.

DEAR MR. STAGGERS: The American Nurses' Association wishes to record its support for H.R. 6430 and H.R. 7688, to amend the public health laws relating to mental retardation to extend, expand, and improve them, and for other purposes. We believe, that at this time, the need for a categorical grant for the development of programs in the field of mental retardation is essential. Until recent years the services available for the mentally retarded were primarily custodial. This legislation, H.R. 6430 and H.R. 7688, when coupled with programs carried out by the Children's Bureau, the National Institute of Child Health and Human Development, and the National Institute of Mental Health will contribute to total efforts aimed at the problems of mental retardation.

As states and local areas develop plans for comprehensive health care we believe that this program should be an integral part of the plans. Mentally retarded persons need the same kinds of services which should be provided for all residents of a community.

The identification of this program as an area of special significance is necessary until the program can be properly assimilated into a comprehensive community health care plan. We therefore support the Mental Retardation Amendments of 1967.

We request that this statement be made a part of the record of hearings.

Very sincerely yours,

(Mrs.) JUDITH G. WHITAKER, R.N.,
Executive Director.

NATIONAL ASSOCIATION OF COUNTIES,
Washington, D.C., May 2, 1967.

Hon. JOHN JARMAN,
Subcommittee on Public Health and Welfare, Committee on Interstate and Foreign Commerce, U.S. House of Representatives, Washington, D.C.

DEAR MR. CHAIRMAN: I would appreciate it if you could make the following a part of the record on the proposed Mental Retardation Amendments of 1967.

"The National Association of Counties supports the proposals, as embodied in the several bills before your Committee, which would extend and expand the present federal matching programs providing aid in the treatment of mental retardation. Our preference is for the total approach of H.R. 5110 which supports a full range of services and provides a more flexible matching formula. We particularly endorse the feature in H.R. 5110 which requires that the Secretary of Health, Education and Welfare give preferential treatment in making grants, to new or expanded services for the mentally retarded that are funded in some part by State or local government. The States and their counties and municipalities must be encouraged to enlarge their interest in providing high quality public care and training programs for the mentally retarded. We believe that the preference clause in H.R. 5110 is necessary inducement to local government action".

NACO also supports the provisions of H.R. 6430 which would extend Part C of PL 88-164, "Grants for Construction of Community Facilities for the Mentally Retarded", which we testified on before your Subcommittee early in April.

Very truly yours,

ED MUNRO, *President.*

(Whereupon, at 11:47 a.m., the subcommittee was adjourned, to reconvene at the call of the Chair.)

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